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ABSTRACT

Twenty-five articles from the bimonthly journal "Rehabilitation Literature" (1959-1984) are presented. The articles were chosen to represent key concepts, principles, and perspectives in rehabilitation. The following authors and titles are represented: "A Concept of Rehabilitation" (H. Talbot); "Rehabilitation: Prospect and Retrospect" (H. Kessler); "A Commitment to Service in Rehabilitation: A Statement of Philosophy" (A. Turiello); "The Issue of Theory in Rehabilitation" (R. Hardy); "The Problem of Personal Worth in the Physically Disabled Patient" (H. Geis); "Emotional Issues in Raising Handicapped Children" (E. Poznanski); "Sexuality and the Handicapped" (M. Diamond); "Toward an Understanding of the Rehabilitation of the Disabled Adolescent" (R. Goldberg); "Concepts of Adjustment to Disability: An Overview" (R. Russell); "The Habilitation Role of the Special Educator" (H. Rusalem); "Significance of Public Attitudes in the Rehabilitation of the Disabled" (G. Roeher); "The Role of Religion in Rehabilitation" (C. Palmer); "The Placement Process in the Rehabilitation of the Severely Handicapped" (W. Usdane); "Physical Rehabilitation and Family Dynamics" (H. Versluys); "Premarital Counseling and the Couple with Disabilities: A Review and Recommendations" (M. Bernardo); "Value-Laden Beliefs and Principles for Rehabilitation" (B. Wright); "Psychological Aspects of Invisible Disability" (D. Falvo et al); "Sexual Dysfunction Associated with Physical Disability: A Treatment Guide for the Rehabilitation Practitioner" (B. Thorn-Gray and L. Kern); "Sensitivity of One Person to Another" (T. Dembo); "Sexuality in the Handicapped: Some Observations on Human Needs and Attitudes" (G. Nigro); "The Ideal Human Service for a Societally Devalued Group" (W. Wolfensberger); "Some Negative Effects on Family Integration of Health and Educational Services for Young Handicapped Children" (N. Doernberg); "Feedback from the Family of Man: Guidance Pointers from Parents of Disabled Children" (I. Robinault); "Vocational Rehabilitation Counseling and Advocacy: An Analysis of Dissonant Concepts" (S. Murphy); and "Cashing in on Recovery: A Challenge for Rehabilitation" (R. Matkin). (CL)

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25 years...
concepts
principles
perspectives

REHABILITATION

25 Years of Concepts, Principles, Perspectives

A collection of articles published in
Rehabilitation Literature
1959-1984

Compiled by
STEPHEN J. REGNIER and MARIAN PETKOVSEK

NATIONAL EASTER SEAL SOCIETY

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Rehabilitation Literature is the bimonthly journal published by the National Easter Seal Society. It is intended for use by professional personnel and students in all disciplines concerned with the rehabilitation of persons with disabling conditions. It is dedicated to the advancement of knowledge and skills and to the encouragement of cooperative efforts by professional members of the rehabilitation team.

Rehabilitation Literature serves to promote communication among workers and to alert them to the literature on development and progress both in their own area of responsibility and in related areas. As a reviewing and abstracting journal, ***Rehab Lit*** identifies and describes current books, pamphlets, monographs, and periodical articles pertaining to the care, welfare, education, and employment of children and adults with disabilities.

Information regarding subscription rates, advertising, and all editorial matters is available from Stephen J. Regnier, Editor, ***Rehabilitation Literature,*** National Easter Seal Society, 2023 W. Ogden Ave., Chicago, IL 60612; (312) 243-8400.

Preface

THIS SPECIAL compilation of major articles from *Rehabilitat[illegible]ature* is a tribute to both the National Easter Seal Society and you, the rehabilitation professional.

In 1959, a decision was made by the National Easter Seal Society to change its reviewing/abstracting magazine into a complete rehabilitation journal—the first of its kind covering the broad field of rehabilitation. The editors solicited articles from recognized leaders in the field, added features requested by readers, and gradually built *Rehab Lit* into the respected professional journal that is now deemed necessary for every medical and rehabilitation library.

The journal offered then, as it does now, not only access to the latest publications in the field but also a constant stream of articles and materials that are current, useful, and authoritative.

From that collection, we have chosen 25 articles that put forth, we believe, the key concepts, principles, and perspectives in rehabilitation.

We know that you, the rehabilitation professional, want only the best to use in your work with people having disabilities—because we operate our agency on that same standard. As you read this book, you will find yourself thinking, responding, and ultimately using the material we have gathered. We are confident that your grasp of rehabilitation philosophy and practice will be strengthened by this book—another of our efforts to achieve our overall mission of promoting "maximum independence of people with disabilities."

As *Rehabilitation Literature* embarks on its next 25 years, it is fitting and proper that former editors Earl C. Graham and Helen B. Crane be remembered for the dedication and skill reflected in the quality of the articles presented herein. We also acknowledge the assistance rendered by members of *Rehab Lit's* 1984 Editorial Advisory Board in the arduous selection process.

John R. Garrison
Executive Director

Introduction

WHEN I BEGAN volunteering in the rehabilitation arena during the polio epidemic of 1949, people with disabilities were regarded not as people, but as patients, who were to be seen and not heard, to be overpitied or overhaloed.

The bathos of the press reflected the public's attitude toward disability. Those who had disabling conditions were referred to as "polio victims" and "cripples" who "overcame" their handicaps with "courage and determination" and "bravely" resumed their lives, "despite the burden of braces and crutches."

Attitudes toward people with disabilities improved significantly as humanistic programs for people with low income and minorities developed in the United States in the 1950s and 1960s. This increasing regard for the rights of all minorities was reflected in the Rehabilitation Act of 1973 and in the development of the independent living movement in the 1970s, which recognized the rights of those with disabilities to choose and to plan their own lifestyles.

These rapid changes in attitudes and programs began to be recorded during the 1950s in periodicals such as *Paraplegia News*, *Performance (Disabled USA)*, *Polio Living (Accent on Living)*, and *Toomey j Gazette (Rehabilitation Gazette)*.

Among these pioneering publications was *Rehabilitation Literature*, then a monthly publication of the National Easter Seal Society. Those early issues of *Rehabilitation Literature*, as well as today's, reveal the same realization of the value of rehabilitation to individuals and to society, the same understanding of the importance of changing attitudes from negative to positive.

The National Easter Seal Society shows its sensitivity to the changes in attitudes and in the recognition of the rights of people with disabilities in its name change from the National Society for Crippled Children and Adults to the National Easter Seal Society and its changing emphasis from working "for" children and adults with disabilities to working "with" them.

Then and now, *Rehabilitation Literature* has published the works of the most influential leaders in rehabilitation and made a very important contribution to the history of rehabilitation. In its 25 years, the excellence and clarity of its contents and editorial policy have never waivered. It continues to render a great service to the national and international rehabilitation community.

Gini Laurie
Editor/Founder
Rehabilitation Gazette
Chairman
Gazette International Networking Institute

REHABILITATION

concepts

A Concept of Rehabilitation

HERBERT S. TALBOT, M.D.

Summary

The rehabilitation process is as rooted in society's values as any of its institutions or cultural endeavors. For rehabilitation professionals in the United States, that means rehabilitation must honor individual choice and encourage self-sufficiency. But, technological devices permitting greater physical freedom, and jobs filling time and wallets, though indispensable, are only components of rehabilitation. The ultimate goal is a patient who finds meaning and pleasure in life and who is prepared to achieve.

People with disabilities are as intelligent, ignorant, enthusiastic, dispirited, virtuous, and egotistical as other individuals. Recognizing and respecting their diversity is the challenge facing the rehabilitation community. Rehabilitation will be realized when patients experience the fullness of their cultural and spiritual heritage and the security of their own individuality.

THIS LECTURESHIP* and this hospital in which it is endowed are symbols of something fine and strong in America and American medicine, the self-sustaining community, pouring its own productiveness into the stream of our national life and reaching out to every corner of the land to maintain the associations that strengthen us all. But it is only fair to warn you at the outset that I bring you no announcement of great advances, so-called, no magic new drugs, no bold new technics. Instead, I shall try simply to share with you some of my reflections arising out of an experience that has been exciting and rewarding.

As it has seemed important to me, so I think it will seem to you, because it concerns itself with an impulse that lies at the heart of our calling, the untiring urge of the physician to make men whole. Further, it carries that impulse into an area of our responsibility that should be peculiarly the province of the local community. Nor is that claim invalidated by the fact that the personal experience upon which it is based was full-time work in a federal service. For just as the chief function of government is to secure the lives and prerogatives of individuals, so it must be the aim of federal medicine to support and supplement individual and community practice. We are all in this together and we must work together.

I

In the complicated way of life we have fashioned for ourselves, no problem exists in a vacuum. No undertaking, however important it may seem to any one of us or even to a great many of us, has any validity unless it be considered in terms of all the problems and undertakings of our varied world. Nor, indeed, can it be thoroughly understood or reasonably approached, save against that broad background.

Rehabilitation, as I shall try to point out, consists not simply of the correction of or compensation for disability, but rather the development of

Rehabilitation Literature, December, 1961—*Herbert S. Talbot, M.D., was chief of urology, Veterans Administration Hospital, West Roxbury, Mass.; lecturer in urology at Boston University; and a clinical associate in surgery at Harvard University.*

a way of living, and this must inevitably be conditioned by the patterns obtaining in the community. Further, it will be rooted in the individual patient's background, hereditary and environmental, and no less in the background of those who try to help him. For the rehabilitative process, like any form of education, is involved as deeply in the motives and purposes of the teacher as of the learner.

It seems to me that the concept I offer you would have been valid in this country at any time in its history, because it is based upon convictions we share with our founding fathers. By the same token, it would seem strange and inappropriate in a totalitarian state, with its lesser concern for the individual and his prerogatives. I once had a visitor to the Paraplegia Service, a social worker from the other side of the Iron Curtain, who asked me what the daily program for the patients was. She was honestly uncomprehending when I told her that this would take some time to describe because there were as many programs as there were patients on the service. Such an arrangement, such meticulous seeking out of individual preferences and talents, would have been quite inconceivable in her country. She registered the usual objections, about the resulting lack of efficiency, that we expect from quarters where efficiency is esteemed more than human dignity. The incident shows what I mean by saying that the answer to any problem must be worked out in terms of the culture in which it is bred. The concept of rehabilitation I am describing has as its chief virtue that it tries to be consonant with the way of life that we, in this country, think is the only way worth living.

Let us begin with a brief historical survey. Even after the practice of exposing deformed infants to the elements to die had been discontinued, and when a cripple no longer went in dread of being killed because he was useless or repulsive, there were yet many centuries during which the best he could anticipate was alms. In time, sanctioned and encouraged by the church, there arose the notion of caring for these people, as of the sick or the blind, and asylums in which they could be looked after were established. One such, founded in France in 1657 and later to become the famous Salpêtrière, was designed as a place in which the infirm could find suitable work, thus jumping the gun on the rest of mankind by a couple of centuries or so. In this, as in other triumphs of the human spirit, voices cried out in the wilderness before there were ears to hear.

Generally, however, the arrangements were merely such as to provide refuge and sustenance, with no idea of restoration to a place in the world and the joy of living. An expressed purpose, in fact, was to keep these unfortunates out of the way lest, by the ugliness of their deformities, they might offend the eyes and the delicate sensibilities of their normal fellows—this in an epoch that offered public executions as an agreeable form of outdoor entertainment. Another aim, perhaps more practical, was to keep the streets and highways clear of beggars.

Strictly speaking, rehabilitation as distinct from care and treatment is not a new idea, any more than was the theory of the roundness of the earth in 1492. But the wide range of its present application and the awakening of public interest are new enough so that the general concept has not yet acquired sharp definition. Its aims have been occasionally misunderstood and its methods occasionally misapplied. Its technics, borrowed from half a dozen arts and sciences—medicine and surgery, mechanics, psychology, sociology, pedagogy, and others—have yet to be co-ordinated to the fullest degree. There may be half a dozen people concerned with the rehabilitation of one man, each of whom quite sincerely thinks that his or her job is the essential one. The fact is that they are all essential, but no one of them is sufficient in itself.

The beginning of the modern trend can perhaps be traced back to early in the 19th century, by which time advances in orthopedic surgery had led to the establishment of the first institutions for the care and treatment of crippled children. As the number of such places increased, the scope of their activities expanded beyond the purely remedial, to include the training of those with residual deformities. Nothing significant was done for adults until about 60 years ago, when the conscience of the race perceived that this vast and tragic waste of human happiness was largely unnecessary. It has required the impact of two world wars to bring us up to date. For, during and after those wars, current methods of treatment returned to the stream of life mutilated, deformed, and variously disabled but for the most part physically healthy young men, in numbers not previously encountered. Never before had so many of the severely maimed survived in such generally good condition.

Physical handicaps are no longer the mark of the congenitally afflicted, or the infirm, or those who never knew life otherwise. They are borne now, in large part, by vigorous young men, who yesterday were among the best we had and who may still be so today. No less in peace than in war, many who would have died a few decades ago now survive, although not unscathed, crippling disease and the accidents of industry and transportation. All these have made the doctrine of rehabilitation a matter of everyday necessity.

But I should like to urge upon you that this is not essentially an economic nor a political necessity, although these people are capable of making great contributions to our productiveness and to the vigor of our national life. It is, rather, a humane necessity, a process that helps us who administer it no less than those who are supposed to be the recipients of its benefits. It is a necessity because we realize at last, or should realize, that we are indeed our brothers' keepers, that, unless we offer to the handicapped the opportunity to live richly and fully, we shall not have lived richly and fully ourselves. I cannot escape the impression that this intensely personal feeling of responsibility—however it may be interpreted psychologically—is essential to the success of our enterprise. That is why I have already pointed out how deeply the process involves the motives of those who are engaged in the work.

II

Neither the disabled themselves, however, nor the public, nor even those who are doing the work of rehabilitation, seem to be altogether clear about what needs to be done nor what can be done, and a few serious fallacies have appeared. There is, for instance, a rather naive notion that practically all of these handicapped persons are potential world-beaters, eager only for an opportunity to display their great talents. This may have arisen in part from a wide, popular acceptance of the Adler theory of compensation, which can be supported by any number of individual instances but seems to fall short of universal applicability. The fact is, of course, that the proportion of world-beaters among the disabled is the same as in the rest of the population, which is to say, small. There are also, just as in the community at large, the lazy, the stupid, the inept, and the unsocial. A great many healthy people without physical handicaps are content merely to get along, and some drift off the pathways of industry and virtue.

Considered in terms of character, aptitude, and good citizenship, it is wrong to expect that the processes of rehabilitation can add much, if anything, to what was there before the disability was incurred. I hope that I may be forgiven for referring now and again to my own experience with the severely disabled. I do so because an undertaking so heavily dependent upon personal relationship can best be described in terms of persons. My work has been among patients with spinal cord injury or disease that has rendered them paraplegic or quadriplegic. What I have learned from them has come from having known them—almost a thousand in all—personally. It would be idle to deny the likelihood of significant personality changes in the presence of such drastic affliction. The extraordinary thing is how seldom they develop in a properly managed rehabilitative environment.

A few, very few, in fact, have failed utterly to make the necessary adjustments, but true psychopathic changes have been even fewer, and these in individuals in whom the tendency was almost certainly present before injury. A small number of my patients came to grief while engaging in criminal activity. All but one now tread the paths of righteousness, suggesting that a broken back is a forceful reminder that crime does not pay. (The exception was one of the psychopaths.) It might also be pointed out, with some truth, that being paralyzed closes the door to the more violent forms of crime. But we like to think that, in an atmosphere of mutual respect and consideration, men may realize, perhaps for the first time, that they get along best by being decent to each other. Improvement of his moral outlook, however, whether in these or in less dramatic instances, does no more than make the patient ready for rehabilitation. How far the process can go must still depend upon his own energy, ability, ambition, and other traits that are difficult if not impossible to fashion or modify.

To rehabilitate, from its original Latin meaning, is to restore, not to create. Having brought a patient to the best possible state of health and provided such mechanical substitutes for his lost functions as are available, we must offer him training, in such degree and kind as he is capable of accepting, calculated to help him to attain a status of dignity and self-sufficiency. In most cases it can be done, although it is seldom easy. Persons without physical handicaps also fail, all too often, to achieve this end. What must be remembered is that, by and large, the quality of the finished product will depend upon the quality of the raw material that went into it. In adults, the raw material of habits, tastes, and social attitudes has already been largely determined. The impact upon the personality of a crippling illness or injury may modify these traits for better or worse, but it does not make a new man. Bitterness, disappointment, frustration, and the boredom of long illness, not to mention physical discomfort, are major impediments to the development of a secure and contented individual, even without the prospect of permanent major disability.

Another important misconception arises out of our national faith in mechanical contrivances as the answers to all human problems. In this there is the danger that, lingering too long with the means, we may never reach the end. Many of our paraplegics, for instance, now own and operate motor cars, but we cannot, on this basis alone, call them rehabilitated. It makes good news pictures, but it is not enough. The public, of course, must be kept informed of this work, but there is no reason for supposing it unable to comprehend fundamentals; too often it gets only the window dressing. Sentimentalizing and oversimplifying are currently popular but highly uncertain means of education.

The gadgets are helpful, often necessary, and they are sometimes (not always, alas) almost miraculously efficient. But in our admiration for the ingenuity they represent, let us not forget that they are only tools designed to help in doing a job. Their mastery does not bespeak its accomplishment. No patient can be blamed for grasping at every mechanical and prosthetic device available, nor for believing that, so equipped, he will have mastered all his problems. It is inexcusable, however, for those whose task it is to train him to permit him ever to forget that none is so well helped as those who help themselves. The great task is not to fashion a man, since that has already been done, but to bring him to an awareness of his own capacities and help him to fulfill himself.

III

Nothing better illustrates the intensely individualistic philosophy that still prevails in the United States, despite the cries of alarmists, than the resistance so frequently offered to rehabilitative efforts. This is seldom overt, being far more often manifested by apathy or lack of interest than by actual hostility. But it is clearly evident that our people, even when disabled, do not take kindly to having their lives worked out for them and the patterns of their existence planned, however benevolently.

During recent years I have had the privilege of visiting a number of rehabilitation centers in this country and abroad and of meeting many foreign colleagues. It has been heartening to observe that, on the highest level of endeavor, equally fine work is being done in many nations. There is, however, one difference worth reporting. Our American patients are less docile than their European counterparts about accepting jobs to which they are directed. This is not simply a manifestation of greater independence because of more generous pensions. It is the vigorous assertion of a man's prerogative to pick his own work, a prerogative which, being based upon specific ability, may not be categorically denied because of an irrelevant disability.

The problem, of course, is to have the ability emerge and develop, to make certain that the disability is reduced to irrelevance. The fundamental choice, however, must be the individual's own, not his doctor's nor his vocational counselor's, nor that of any of the host of people whose knowledge and skills qualify them to help but not to direct. No point needs more earnestly to be stressed than the need for being humble with those we wish to help. The absence of such humility is responsible for many of our failures. The very heart and essence of rehabilitation is self-sufficiency; it cannot be nurtured if it be denied at the outset. The greatest handicap of a disabled man is not the physical impairment itself so much as the fear that, because of it, he may be unable to follow his own bent and make his own choices. These, after all, are the prerogatives of that freedom to which we pay such constant lip service. The obligation that lies upon us is to show the patient that he can still make his own choices; it is not for us to make them for him.

This, of course, means that we must be prepared to teach, to encourage, to advise, but never to dictate. It means, too, that these men and women must be allowed to make their own mistakes, as we all have done. This may be very trying to the beholder, for it is not easy to be sympathetic with a course of action with which we disagree. Finally, it must be acknowledged that there are those who cannot be rehabilitated in the fullest sense. Some would not in any circumstances have become self-sufficient to the degree idealized in a free society, and for these we must be content with lesser achievements. It is no discredit to the whole work that not all of its results will be of equal excellence—not as long as we recognize clearly the difference between a finished job and a makeshift. It is helpful sometimes to be able to take refuge in a sense of humor. Heavyhandedness is very wearing, but every doctor knows how much comfort there may be in the appearance of casualness. Chesterton once wrote, "What can one be but frivolous about serious things? Without frivolity they are simply too tremendous." I am not quite prepared to recommend an attitude of frivolity, but a light touch causes no pain.

The economic factor has brought further confusion to the issue. While it is quite true that financial need is an important stimulus to a man's determination to rise above his disability, it is also true, now as ever, that man does not live by bread alone. The concept of self-sufficiency should not be limited to the economic sense, although that obviously must be included. There are times, in fact, when I wonder if we are not deceiving ourselves, mistaking a makeshift for a finished job, simply because a man is earning a living. I expressed this doubt some time ago in an article written for a journal in England and was interested in finding confirmation, in the next issue, in a letter from a paralyzed reader. He wrote in part: "To so many people a return to work approximating to the sort of work done prior to injury is synonymous with a return to the natural order of things. There is surely much more in life than just being cooped up in a factory or an office. Mental health is surely the primary condition, and I remain unconvinced that the only way to achieve that is by finding the patient a job. Satisfaction at being economically independent will not, I submit, compensate in the long run for an uncongenial job."

Motivation is a word glibly used—often too glibly—but it represents a complex of emotional and intellectual elements not easily identified, much less measured. Certainly, it is a reasonable assumption that most people work in order to earn money. As I write these words I am reminded of Dr. Johnson's famous remark, "No man but a blockhead ever wrote except for money." But its full significance lies not in the implication of his disinclination to write for nothing, but rather of his choice of writing as a means of earning. Incidentally, he also said, "Men are seldom more innocently employed than when they are honestly making money."

Among my own patients and former patients, I have observed with interest that those who receive the most generous pensions, *i.e.*, those who became paralyzed while in service, are by no means the least assiduous in looking for, landing, and holding jobs or in engaging successfully in some form of self-employment. On the contrary, I believe that their record in this respect is rather better than that of their nonservice-connected comrades, whose pensions are adjusted to a mere subsistence level. Without speculating about the reasons for this, it is sufficient to suggest that actual need for money is not the only determinant for working, nor the amount earned the only criterion for the choice of work.

There is yet another sense in which, I believe, the economic aspect of rehabilitation has been falsely stressed. It has been considered necessary by some to "sell" the idea of rehabilitation by pointing out that it is cheaper for the community in the long run—cheaper, of course, in a pecuniary sense. The argument goes something like this: First, when these people have been brought to the point of earning their own livings, the public treasury, be it local, state, or national, is relieved of the drain of supporting them; second, they earn enough so that the taxes they pay more than balance the costs of their rehabilitation. Statistics are brought forward to prove this, as, indeed, they can be to prove anything. But suppose that the taxes paid by these people came to only one half of the sums expended in their behalf, or one quarter, or one tenth? Is there a point at which we might decide that the return did not justify the outlay and that our endeavors were, in consequence, unjustified? Is rehabilitation, indeed, a luxury to be indulged in only so long as it pays or breaks even, or an obligation of human decency to be met at whatever cost? Perhaps it is important to be assured that we can afford to carry on this work. Can we, believing what we do believe, afford to do otherwise?

The sort of argument I have just mentioned not only does grave injustice to the spirit of our people, it is a disservice to the cause of rehabilitation because it obscures its chief purposes. These, I insist, are fundamentally humane and not economic. If our efforts are to be inspired or even chiefly encouraged by the fact that they are going to save us money, then we come off second best by comparison with our ancestors who left their disabled on a mountain top. At least, they were not expected to return a profit. If the total amount of these taxes is cause for any satisfaction at all, it must come to those who pay them, from the knowledge that they are playing their part in the community.

No one but a fool denies the importance of earning a living. But simply to do so no more constitutes the complete rehabilitation of a disabled person than it would imply a complete and satisfying life for any other individual. Like the mechanical gadgets, it is a means and not an end. Any man, disabled or not, should do something with himself—something from the doing of which he can derive satisfaction and augment the sense of his worth as an individual, something from which, also, he can earn enough money to meet his particular needs. The true criterion of successful rehabilitation is not making a living but finding a satisfactory way of life.

IV

Educators say of a college that its function is not so much to give its students learning as to open their eyes to the truth and teach them how it may be sought. Similarly, the process of rehabilitation must open a man's eyes to what he wants to do with himself and help him to achieve his aims. It is a process that must begin at the very onset of the disability, for it demands, from the beginning, a reasonably satisfactory adjustment by the patient to the modifications of activity that have been imposed upon him. And it is a process that, in its most successful application, never ends. For rehabilitation is not a sort of degree or mark of distinction granted at the end of a course. It is, rather, a state of being to which one aspires, more or less approximated in various instances but never fully realized. It is a way of life.

Obviously, good health and its accompanying sense of physical well-being are highly desirable and may be set down as essential prerequisites. Despite serious gaps in our knowledge, more is possible now in this direction than ever before. With certain exceptions, most disabled persons may now expect lives of reasonable comfort and normal duration. In our enthusiasm over the fine results of our increasing medical and surgical skills, however, we forgot for a time that they were doing only half the job. They were making life longer and more comfortable, but not necessarily more worth living. It was, perhaps, natural that, when the medical profession began to assume in earnest its obligations in respect to rehabilitation, it should have emphasized those physical aspects for which the knowledge and technics were at hand.

As doctors, however, we have not yet brought the best of our philosophy to bear upon the essence of the problem. It has always been our noblest aim to treat man and not disease, however we may have strayed occasionally from this high purpose. Moreover, we are more and more being urged, and urging ourselves, to treat the whole man. When a patient presents himself, we do not stop at the chief complaint but work him up completely. We are not, nor should we be, satisfied with any course of treatment that does not meet all the needs we have uncovered, regardless of whether he was himself aware of them in the beginning. Everyone has heard of the poor chap who comes in with some minor complaint or other, gets a wonderful work-up, and leaves the hospital, some weeks and an operation or two later, with his original complaint still untreated.

But when a disabled patient presents himself, we find it difficult to see beyond the disability itself, the missing or paralyzed limbs, the deformity, the loss of vision or hearing. Yet this is but the presenting facet at which the physician articulates with the patient. Behind it is an organism, a personality desperately needing to regain an image of itself in which will be preserved the precious core of individuality. We must study and understand the whole organism, the whole personality.

It is through no virtue of our own that a few have had this realization thrust upon us. The patient with a spinal cord injury presents, along with the obvious paralysis, such a variety of grave complications, autonomic, visceral, cutaneous, and the like, that his very survival requires the most painstaking observation and management. In fact, until the period of World War II, not enough such patients survived for more than a few months to attract general attention to their needs. Now there are probably more than 50,000 in this country, some say as many as 80,000, and those who are charged with their care must treat the whole man indeed or there will be none to rehabilitate. It has been an extraordinarily rewarding experience from which we have learned much that is applicable elsewhere in medicine and surgery. But, in particular, we have learned from these patients how to approach all the severely disabled, to recognize their particular needs, and to appreciate the almost unbelievable courage and resourcefulness with which they face the most formidable handicaps.

Because of the variety of patients' requirements, a high degree of specialization in treatment has been inevitable. The specialties are necessary, but someone must know the whole patient and know him well. Someone must draw the varied efforts together into a master plan, be aware of everything that is going on, direct the whole undertaking. Whether or not he contributes one of the special skills himself is less important than that he should understand the right time and place for all of them in each individual case. In short, the relationship of doctor to patient must be as intimate and direct, as charged with mutual confidence as has ever been idealized as a standard of practice. There is no more essential element than this in the concept I am trying to describe. Rehabilitation cannot be turned over altogether to specialists and special clinics. They have their part to play, but the key figure is still the patient's doctor. Whether he be a family doctor in private practice, or one of the team of specialists, or a full-time doctor in a large center is unimportant, but he must be there. Whatever its other implications, rehabilitation is a medical problem, and there is an essential quality in the physician-patient relationship that cannot be delegated.

For all this, we must recognize our limitations. In problems so highly individualized as those of rehabilitation, our insights will not always be sufficient. This is not a council of despair but a reminder to be humble. Plastic surgery, prosthetic appliances, and the fine accomplishments of physical medicine have all contributed immeasurably to equipping and preparing the disabled for useful and contented lives. But in themselves they may not get down to the essence of a man, and, if he has not within himself the desire for accomplishment, his response to all these efforts will be at best mechanical. For all our methods of medical and psychological investigation, we cannot reach into the secret places of the heart. We may stimulate and persuade, but the essential response must arise in the patient himself, and the sooner this is generally realized, the sooner it is acknowledged that most of the things we have been calling rehabilitation are not that but only a means to it, the sooner we shall have the results we want. Up to now, too much emphasis has lain on processes and technics, too little upon the individuals to whom they are applied.

It is not too difficult to provide a man with a pair of artificial legs and teach him to walk upon them. The next question is where will he walk? There is no determination in the legs themselves, but the manner and direction of that determination are none the less a part of rehabilitation, concededly the most difficult part. Paradoxically, it is just that individuality which we must so sedulously cultivate and encourage that places so many obstacles in the way of success. Unless it is encouraged, however, there can be no success worthy of the name. It is possible now for many, if not most, physically handicapped persons to get gainful employment without the onus of "made work." But in any given case we must ask as well, was this the work he chose for himself, or was it chosen for him? Was he discouraged from trying something else he preferred, or was encouragement lacking for a venture he wanted to try but feared to risk? Whatever aid he got, whatever training, whatever gadgets, was he permitted to make up his own mind, to choose his own way?

In promoting the cause of their rehabilitation, many have referred to the waste to society represented by disabled persons. The real waste, however, is not of so many mechanics or scholars or artists or scientists, but of the human beings who play these parts. The greatest danger a disabled man faces is not that he may lose his earning power but that he may, in boredom, apathy, and despair, lose the awareness of his own worth and dignity. The material phases of the problem, although not fully mastered, are at least well in hand. The time is come when, if the work is to be fruitful, we must reach toward those intangible values that give life meaning and savor—toward a concept of rehabilitation that recognizes that man is, or is capable of becoming, a spiritual being. In this lies his capacity to overcome almost any physical handicap.

What, then, are we striving for? What is this concept all about? If all the things we generally call rehabilitation are simply a means to an end, what is the end itself? What is it that the disabled man must recapture in order that he may fashion a new and acceptable image of himself, overcome the handicap of his disability, and achieve self-sufficiency in so far as any one can in this crowded world? If you must have it in a few words—and I do owe you some effort to be concise—I should say that our man must find restored to him a sense of the security of his own individuality. If there is a keystone supporting the structure of our concept, this is it.

It may immediately be objected that this is inconsistent. For I have said that our undertaking must reflect the time we live in, and certainly one of the recurrent themes of life today is a lurking sense of insecurity. It is true that I cannot expect my patients to achieve a sense of security in a military or economic or political sense any firmer than that which supports most of us in these uncertain times. I may hope, as a physician, to be able to offer him security of his person to the extent of reasonable health and comfort. But the security of his individuality, drawn from an inward strength, will render him capable of standing up to any threat, at least as well as the rest of us do.

He cannot be spared, any more than we can spare our children, the trials all men must face. To each era of history comes its own problems, nurtured in the great intellectual currents that sweep across the earth from time to time. Today, we of the Western World are struggling to free ourselves from the trammels of materialism even as we must strive to make ourselves materially stronger. That is the desperate paradox we face and which we must resolve. We can do so only by reaching back and re-establishing the spiritual values that first gave us courage, confidence, and strength as a nation. This is the great problem of our generation. It is the chief problem of education: to learn the values that transcend material considerations and at the same time achieve mastery of the intricacies of our material culture. It is certainly the chief problem in rehabilitation, precisely because we have come to put so much faith in gadgets and medical skills, inadequate as they are, that there is a danger that our patients will depend upon them rather than simply use them for what they are worth.

It is, perhaps, a symbol of what I seek for the disabled, that in my general associations with most of my former patients, I am scarcely ever consciously aware of their disabilities. This is not merely a glossing over, or a matter of habit. Among those currently under treatment the same disabilities are a matter of constant preoccupation. The attitude, in fact, is not of my making but theirs. They bear their handicaps with a sort of grace that makes them unnoticeable. This also is a part of rehabilitation. Our concept is not made up entirely of intangibles. But, in the physical realm, we have reversed the old attitude; we concentrate on the abilities that remain until the disability seems, by comparison, less significant. I honestly think that in some instances it becomes, even for the patient himself, insignificant. For he has filled his life and his mind with things to do until he no longer misses the things he cannot do.

There is a theory that no severely disabled person, however intelligent and understanding, however clearly he acknowledges his predicament on the conscious level, ever actually accepts, in his subconscious, the permanence of his dysfunction. I have discussed this with many patients and perhaps half of them think it may be so; the other half doubt it. I have no firm opinion myself, and it seems unlikely that we shall ever have sufficiently extensive psychoanalytic studies to give us much sound evidence one way or the other. But this I do know: The great majority of these people, whether or not they have accepted the permanence of their disabilities, have made good preparation for a long siege. If some day the siege is lifted, fine. If not, they will not have wasted their time.

Whatever they can or cannot do physically, however great or small their handicaps, often in spite of discomfort and poor health, most of them are sure of themselves, satisfied that life is worth living, and doing their best to live it fully according to their several abilities. Most important of all, they are living their own lives, making their own choices, enjoying their rightful heritage.

So the goals we seek in the rehabilitation of the disabled are none other than those we should choose to see established for all, handicapped or not. We have come the full circle. I began by saying that the validity of our undertakings depends upon their fitting into the pattern of our culture. Now, as I close, I hope you will agree that the concept I have tried to define fairly reflects the meaning of our democratic ideal, our Christian ethic, our American tradition.

Nothing less will do.

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Rehabilitation: Prospect and Retrospect

HENRY H. KESSLER, M.D., Ph.D.

Summary

Public rehabilitation policy in the United States began as vocational training for injured soldiers returning from World War I. Military and civilian groups doggedly maintained their respective medical and vocational responsibilities, often leaving soldiers in limbo between military hospitalization and private life. Civilian rehabilitation legislation that created federal-state partnerships emphasized vocational training but excluded comprehensive therapies and education. Not until World War II produced thousands more men with serious disabilities did military and public institutions provide physical, psychological, and vocational services to enlisted men.

The humanitarian movement on behalf of children with disabilities pushed international and American rehabilitation policy toward the total care concept. Contemporary facilities, while struggling to integrate services, are falling short. To serve their clients well, institutions must adapt to the ever-changing political and social philosophies of rehabilitative care.

"HE WHO NEGLECTS history will be condemned to repeat it." This advice by the philosopher Santayana appears to be especially applicable to the concept of rehabilitation. Though rehabilitation was begun as a great challenge in solving the problems of the physically handicapped, its promise has never been fulfilled.

Rehabilitation as a dynamic force directed towards changing the lives of the physically handicapped from a depressed status in society to one of social and economic acceptance and independence was the outcome of the needs of three groups: the war disabled, the injured worker, and the crippled children.

The essential premise of this concept was an integration of medical, social, educational, and vocational services leading to the absorption of the disabled into society as satisfied social beings acting as profitable, productive economic units. Only by total care of the patient and by maximum development of all of his remaining mental and physical powers and vocational skills could this aim be realized. This was, of course, a most noble sentiment. But prayer is no substitute for hard work or interpersonal human understanding.

For centuries the status of the physically handicapped ran the gamut of prejudice, neglect, and fragmentary social action. The Nineteenth Century witnessed a surge of human conscience, with the establishment of institutions in Europe and the United States providing isolated services of medical and custodial care, educational services, and occasional trade training. It was the last activity that took on greater popularity and action just before the outbreak of World War I.

In 1909 a trade school for the retraining of disabled miners was established in Charleroi, Belgium, under the directorship of M. Azer Basèque. The school survived under his supervision until 1914 when the Germans overran Belgium and Charleroi. M. Basèque found refuge in Lyons, France, where Mayor Edouard Herriot was plagued with a problem of hundreds of war invalids.

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M. Baseque's presence soon solved the problem, and a training center for the war wounded, L'Ecole Joffre, was established. From this experience more than 100 secular training centers were established in France.

In England the Lord Roberts Memorial Workshops followed a similar pattern. The original one at Shepherd's Bush Military Orthopaedic Hospital, London, was especially renowned because of both the association of Sir Robert Jones and the sponsorship of former King Manuel of Portugal.

Italy developed agricultural schemes for its disabled soldiers, while Germany created an outstanding establishment for trade training at Düsseldorf.

In Canada, the Invalided Soldiers Commission took over the responsibility for providing rehabilitation services for the war wounded and the vocational secretary, Mr. T. B. Kidner, was most helpful in providing advice and counsel to the American legislators in the hearings preceding the passage of the federal Vocational Rehabilitation Act of 1918, also called Soldier Rehabilitation Act, which provided services for the war disabled.

A key person during this transitional period was Douglas C. McMurtrie, who also gave testimony at the legislative hearings. As director of the Red Cross Institute for Crippled and Disabled Men in New York City, he was an ardent advocate for comprehensive services for the disabled soldier or civilian. The establishment of the Red Cross Institute, later the Institute for the Crippled and Disabled, was largely due to the generosity of Jeremiah Milbank. The Institute provided trade training for disabled men but gave some attention to physical restoration services by the establishment of a large shop for the manufacture of artificial limbs. McMurtrie collected considerable information in this field, gleaned from both allied and enemy sources, making the Institute an indispensable fountainhead of information in this area. A limited program of medical treatment was carried out in conjunction with a nearby clinic for functional re-education.

As president of the Federation of Associations for Cripples, organized in 1912, McMurtrie was closely identified with the problems of the severely disabled as well as the war wounded. He assisted in the drafting of the first rehabilitation legislation in New Jersey, in collaboration with Dr. Fred H. Albee, the chairman of the New Jersey Rehabilitation Commission. It was at the latter's insistence that I spent the year 1920 at the Institute learning all I could about artificial limbs and familiarizing myself with the vocational aspects of rehabilitation.

It was the impact of the services for the war disabled in Europe and Canada that led to the establishment of public services in the United States, first for the war disabled and later for the civilian disabled. This began in 1918 with the passage of the Smith-Sears Act. Congress, having declared war in April, 1917, was concerned about the welfare of the returning war disabled and prepared plans for their vocational rehabilitation and return to civil employment following discharge from the military or naval forces of the United States. The responsibility for carrying out this service was placed in the hands of the Federal Board for Vocational Education, a civilian organization.

In studying the hearings that took place before the Act was passed, it is interesting to observe that both the military and civilian groups involved were concerned about, if not insistent on, maintaining a dichotomy of control of services. Surgeon General William C. Gorgas wanted the Act thoroughly clarified so the whole physical restoration program of services, including medicine, surgery, and functional re-education, would be under complete control and discipline of the military and naval forces. The Federal Board for Vocational Education respected this position and assured the military that they would not step in until the patient was actually discharged from the service.

Thus, a considerable period of time was lost that might have been utilized in evaluating the patient's potentials and preparing adequate social, psychological, or vocational plans for his resettlement. Furthermore, a man who lost his limb in service was forced to wait until his discharge before an attempt would be made to secure an artificial limb, while care of his stump and training in the use of his prosthesis were also left to chance after his discharge.

However, while the military and civilian groups, so concerned about the welfare of the returning disabled war wounded, observed their traditional arbitrary positions, certain doubts began to emerge in both camps that gave them much disquiet. Occupational therapy was having a great boom in England and Canada and rumors of its advantages reached down into many of the military hospitals. As a matter of fact, it was Miss Elizabeth G. Upham, a director of a college art department who was interested in social work, who sought to gain Mr. Milbank's interest in establishing an occupational therapy program in the United States. Out of this beginning Mr. Milbank proceeded to the establishment of the Red Cross Institute in 1917.

Many volunteers offered their services to the military hospitals. Compromises had to be made to accommodate these civilians in the strict military routine of the traditional military institutions. To deprive the war wounded of the advantages of this new technic would have been a great embarrassment for the military. On the other hand, Col. Frank Billings, of the Surgeon General's office, speaking for the military questioned the wisdom of waiting for formal vocational training to begin after discharge from service, when much planning and even training could be done while still in hospital and in service. He cited the case of the disabled telegrapher who taught 10 other patients the rudiments of telegraphy in the hospital.

In other words, while the military and civilian groups were dogmatically observing their medical and vocational prerogatives, they sensed the presence of a grey overlapping area. Yet their traditions were too strong to be broken, and synthesis had to wait for another day.

During the course of the hearings on the Smith-Sears Bill, strong overtures were made to include disabled workers in the benefits of the Act, but the legislators preferred to wait until 1920 to enact civilian rehabilitation legislation. The 1920 Act established a new pattern in that the federal government went into partnership with the states in providing benefits to disabled workers and civilians. Again the services were essentially confined to vocational training, and the supervision was to be in the hands of educators, the Federal Board for Vocational Education. A limited inclusion providing artificial limbs was the only concession toward the provision of physical restoration services. Dr. Harry E. Mock, who gave testimony during these hearings, made an impassioned plea for comprehensive services to include physical restoration, but this was ignored.

In the meantime the impact of the 1918 Smith-Sears Act and the hearings that preceded its passage was sufficient to stir state legislatures to enact laws establishing rehabilitation programs. Although 12 states did so before the federal Act of 1920, only 6 were actually in operation when the first federal law was passed. Among these was New Jersey, which had set up a program in early 1919.

The architect of the New Jersey program was Gov. Walter Edge, later United States senator, ambassador to France, and again governor of the state. He had been instrumental as a state senator in introducing the Workmen's Compensation Law in New Jersey in 1911, the first held constitutional and hence the first to be operative in the United States. Gov. Edge brought together the State Commissioner of Labor, Col. Lewis T. Bryant, a tall, six-foot-four man, horribly crippled by arthritis deformans, and Dr. Fred H. Albee, the famous orthopedic surgeon of the World War I period.

Dr. Albee, who had been brought up on a farm in New England, had learned the principle of tree grafting from his grandfather. By experimenting on dogs he was able to apply this principle to humans, developing the bone graft. The application of the bone graft to the cure of bone tuberculosis, especially that of the spine (Pott's disease), brought him worldwide acclaim, and the Albee operation became the standard treatment for spinal bone tuberculosis around the world.

Thus, he soon became an international figure, demonstrating his work abroad in 1913. Soon after war broke out in 1914, he was invited by the Germans, the French, and the English to demonstrate his methods and his ideas as they might influence the recovery of war casualties.

In 1916 he made a tour of over 40 military hospitals in France and concerned himself not only with the specific treatment of severe war wounds but also observed the first meager steps being taken toward the resettlement of the severely disabled. In England he worked in close collaboration with Sir Robert Jones, whose broad vision saw beyond the operating room and visualized the need for an aftercare program that would favor the return of the war wounded to a productive place in the community.

On a visit to Canada in 1917 Albee was again inspired by the early attempts being made to attack the problem of the total needs of the war wounded. He saw the failure of the one-dimensional, isolated approach of the past and the need for a comprehensive program to meet the needs of the disabled.

Accordingly, he wrote to the War Department pointing out the need for establishing facilities in the United States that would include all the services before a patient left the institution rather than the unfinished fragmentation of services that would only leave the discharged disabled person to have nothing to look forward to but philosophy.

The Surgeon General was in accord with his suggestions. Plans had been for three institutions to be called reconstruction hospitals. These were to include all medical and surgical facilities as well as vocational guidance and training courses to prepare the disabled soldier for resettlement.

Although these three institutions were planned and projected, only one of them saw the light of day, Reconstruction Hospital No. 3 at Colonia, N.J. Dr. Albee was placed in charge of this institution with the rank of colonel. Here he was given every opportunity to develop his ideas, and here he expressed his philosophy in the only public or private institution in the United States ever to achieve this integrated program of medical and nonmedical services to rehabilitate disabled persons. Every medical and surgical service was available, with physical medicine in all its forms, including physical therapy, occupational therapy, functional re-education apparatus of the R. Tait McKenzie type as well as the Zander type, hydrotherapy, and gymnastics. Artificial limb, psychological, and social services and more than 30 trade training courses were available. Workshop personnel, placement officers, and social workers supplemented this work to facilitate the transition from the service back into industry after discharge.

The Hospital was built to accommodate 2,000 beds. More than 6,000 war wounded were treated during the 16 months of its operation from July, 1918, to October, 1919, under the supervision of Dr. Albee. Here were applied all the lessons that Albee had acquired from his experiences in Europe and Canada for the complete care necessary to resettle the war wounded.

During the hearings on the federal Act of 1918 and again the Act of 1920 references were made by many of the speakers who testified to the need for changing the public attitude toward disabled workers. As one speaker said, We have come to realize that this country from its foundation sent the disabled men of industry, the victims of industry, to the waste pile. We have had so much cheap human labor to use that we have neglected our crippled and handicapped in the most indifferent way. The people of this country are determined that this shall not happen again at least with the men who come from the war.

The first national program of federal-state cooperation to restore men and women became a reality when the President on June 2, 1920, signed the National Rehabilitation Act (Public Law 236, 66th Congress), commonly known as the Smith-Fess Act and sometimes referred to as the Fess-Kenyon Act. The primary aim of this Act was directed toward the rehabilitation of disabled workers. Its passage was supported by both political parties and the National Association of Manufacturers, the American Federation of Labor, and numerous other organizations representing social welfare, medicine, education, and government. It is obvious that it drew its inspiration from the 1918 Act on behalf of disabled soldiers.

In this initial program, jointly financed and developed by the federal and state governments, the services for the handicapped consisted of special assistance in job training, counseling and guidance for the disabled person, provision for artificial limbs and other prosthetic appliances, and placement in a suitable job. The state was required to invest one dollar of its own funds for each dollar of federal grant funds received.

As has already been mentioned, New Jersey passed its rehabilitation act and went into operation in 1919, a year before the federal Act was passed. When the only reconstruction hospital for disabled soldiers was established in New Jersey, Gov. Walter E. Edge naturally viewed this achievement with great pride. He prophetically saw the possibilities of rehabilitation as it applied to the injured worker. He brought Col. Bryant, the state's Commissioner of Labor, together with Dr. Albee and, with the help of Douglas C. McMurtrie of the Red Cross Institute for Crippled and Disabled Men, they drafted the New Jersey Rehabilitation Act.

Gov. Edge appointed a Rehabilitation Commission to administer the act consisting of the State Commissioner of Education, State Commissioner of Institutions and Agencies, representatives of labor and management, the Commissioner of Labor, Col. Bryant, who became the director, and Dr. Albee, representing the medical profession, who became the Chairman of the Commission, a post he occupied from 1919 until his death in 1945.

Dr. Albee proceeded to emulate the experience he had at Reconstruction Hospital No. 3 at Colonia, N. J. But with a first-year appropriation of $5,000, it was necessary to curtail any grandiose plans. Nevertheless, he insisted that if rehabilitation was to mean anything it had to embrace the three fundamental legs of a tripod; namely, physical restoration services, vocational guidance and training, and placement. This became the fundamental premise of the philosophy of the New Jersey Rehabilitation Commission throughout its entire career and was pursued with an apostolic zeal. It was expressed succinctly by Dr. Albee when he said, "Never train a man around his handicap." First eliminate his handicap by surgery, prosthesis, or physical therapy, then proceed with the vocational aspects of his program.

Naturally, this philosophy was unacceptable to the federal officials who were primarily educators and hence concerned with trade training only. This became a source of conflict and friction until the federal government saw the light with the passage of the Barden-LaFollette Act (Public Law 113, 78th Congress) in 1943, 24 years later, providing increased services in the field of physical restoration.

In spite of limited funds, Dr. Albee established the first state-operated rehabilitation clinic in the country. An industrial loft was rented in Newark and equipped with an operating room, a physical therapy department, a curative workshop, which, along with a staff of vocational counselors and placement officers, gave him a complete organization for the rehabilitation and resettlement of the disabled workers and civilians. In other words, he was establishing a replica of his reconstruction hospital, but in doing so he insisted on carrying out the principle of a total program to meet the total needs of the disabled worker. In spite of the inadequate physical facilities, he never swerved from his fundamental ideas.

In the same building there were established the hearing rooms of the Workmen's Compensation Bureau, so that disabled workmen could readily avail themselves of the broad program of rehabilitation services that had been established. Later, five other similar clinics were established in other parts of the state, although operating room and similar surgical facilities were not available in these clinics.

My role as assistant to Dr. Albee from June, 1919, was a two-fold one. My first responsibility was to estimate the permanent physical impairment following industrial injuries, on the basis of which financial compensation would be paid. At the same time, it was my additional responsibility to select those patients with severe physical impairments who could be helped by rehabilitation and reconstruction procedures and arrange for their further medical and surgical care.

As all patients were injured workers, the complete control over the program of medical care was in the hands of the insurance companies. Unfortunately, in spite of the importunings of Dr. Albee and Col. Bryant, the companies failed to cooperate. Anxious to dispose of their cases with financial settlements, they saw no moral or legal responsibility to go beyond the extremely limited provisions for medical benefits in the Workmen's Compensation Act. Here was a golden opportunity to do for disabled workers what the government was doing for the war wounded, but a narrow, immediate, parochial, economic interpretation deprived the public of a greater economic and social opportunity. As workmen's compensation has continued to drift during the past 50 years from a hopeful blessing to all injured workers to a gambling arena and bazaar for hungry litigants, rehabilitation has been stomped, strangled, and emasculated by the demon of indemnity.

Canada, however, saw the light and today shines as a beacon of help and understanding in its management of its disabled worker. The central core of its program is rehabilitation, and indemnity is a secondary consideration. In the United States no strong voice has been heard to counteract this great miscarriage of justice, and so compensation continues its daily pathological computation of "disability" while ignoring human suffering and human potentialities.

Because of frustration in attempting a rehabilitation program for injured workers, Col. Bryant turned his attention to nonindustrial cases, the so-called otherwise disabled group. Today, these make up the bulk of the program. From time to time attempts are made to reintroduce the original program for injured workers, but the opposition to such a program is so great that all efforts are futile and wasteful.

With the advent of World War II, it appeared as if the lessons of World War I would again be forgotten and many of its failures be repeated, namely, to allow patients to leave the hospital without having completed a rehabilitation program. The experience at the U. S. Naval Hospital at Mare Island, Vallejo, Calif., was a case in point.

In the early days of World War II a few amputees left the service and necessarily sought limbs from commercial limb manufacturers. As frequently happens, complete services with adequate management of the stump, limb fitting, and services and training in the use of the limb were rarely combined into a complete program due to lack of facilities as well as time, money, and knowledge. The complaints of the parents of these boys who had "given their limbs for their country" soon reached the ears of members of Congress.

At the Mare Island Naval Hospital, Dr. Douglas Toffelmier initiated a program of limb manufacture that later developed into a vast enterprise caring for the needs of 7,000 amputees. It was my privilege and that of my successor Capt. Thomas Canty to carry out this program to its completion. Here for the first time a complete service was provided in the United States for the amputee before his discharge from service. This included, first, psychological preparation of the patient with a full explanation of the processes of rehabilitation and familiarity with all the changes that could be anticipated.

Second was the revision of the amputation stump and employment of special surgical procedures such as cineplasty and the Krukenberg operation. In the cineplasty operation a canal is made in the muscles of the stump, through which an ivory peg is passed and attached to an artificial arm or hook, thus utilizing the muscle still remaining in the stump to operate the terminal device of a prosthetic appliance. The Krukenberg operation consists of splitting the forearm, making two long fingers out of the stump, thus providing both retention of the sensation at the end of the stump and also the ability to grasp and prehend with the two fingers of the stump.

Third, a special program, not only for shrinking the stump but for preventing and correcting contractures, was undertaken. Preprosthetic exercises supplemented this program, in which the stump was given special consideration as a pathological organ.

Fourth, a staff of more than 100 men was trained in prosthetics to design, align, and fit artificial limbs, utilizing all the latest materials, including for the first time plastic material.

Fifth, finally the patients were trained to use their prostheses, both arm and leg. This is a feature of amputee rehabilitiation that is frequently overlooked: The person is given a prosthetic appliance and told to go out and use it. This is as silly as asking a man to go into a music shop, buy a violin and go out and play Bach and Beethoven. The patient needs training in the use of his appliance. With the lower extremity, he must be trained, not to walk but to balance himself, since walking is nothing more than losing your balance and regaining it. In the upper extremity, the loss that a person realizes most is the loss of sensation or touch. This can never be reproduced. As part of the psychological preparation, the patient is made to realize the limitations of prostheses and how his prothesis could be utilized satisfactorily through systematic drill and training.

Capt., later Admiral, J. P. Owen was enthusiastic about the program and, after viewing a film from the New Jersey Rehabilitation Commission program, agreed to introduce additional services so as to complete the patient's physical and vocational recovery before discharge. Thus, we were able to bring all of the advantages and experience of the New Jersey Rehabilitation civilian program and make it available to the amputees and other disabled personnel at the Naval Hospital.

A team of psychologists, educators, physical and occupational therapists, athletic coaches, and amputee trainers from Red Cross supplemented the medical and surgical work of the medical officers, thus providing a maximum physical restoration program for the patient.

At Napa Junior College, 10 miles away, more than 40 trade courses were established to provide short and long-term vocational training courses for analysis of the potentials and aptitudes of the disabled person as well as to provide him with basic training. The University of California assisted by admitting some of our amputees to many of their courses. The California Rehabilitation Commission lent its good offices. All the resources of the Naval Shipyard at Mare Island and of the San Francisco Bay area were utilized in providing guidance and training facilities for the enlisted personnel. Courses were held not only in these outside institutions but also within the hospital itself. Because of this program, the Hospital and the Navy received the Lord and Taylor Design Award in New York City in 1944.

One false note conjured up the old tradition of dichotomy of services when, in early 1946, we were visited by a line officer from Washington who insisted that we sever our relationship with the civilian California Rehabilitation Commission and curtail our program by eliminating everything but physical restoration services. No reason was given and one could only conjecture that the ghost of an earlier bureaucratic regime had reared itself again.

Parallel to this movement on behalf of the war wounded and the industrial injured was the religious, humanitarian, and philanthropic movement for the care of crippled children that saw its dawn in the early Nineteenth Century. The Twentieth Century saw the development of many institutions and organizations again concerned with isolated services for these unfortunate children. The philosophy of total care spilling over from the war wounded and industrial injured soon pervaded the efforts of many of these organizations and institutions. Thus the International Society for Rehabilitation of the Disabled, formerly the International Society for the Welfare of Cripples, and the National Society for Crippled Children and Adults adopted the principle of total care for the total needs of the crippled child.

In 1949 the United Nations passed a resolution favoring technical assistance to all nations in the development of rehabilitation services along these lines. The World Veterans Federation in 1950 adopted a similar rehabilitation scheme as part of its activities.

The rise of physical medicine as a specialty and the development of the field of geriatrics gave special emphasis to the integrated program of services that we call rehabilitation as a basis for meeting the needs of the expanding group of disabled people.

By 1954 it became evident that the rapid changes in rehabilitation in the United States and elsewhere called for revision of federal legislation to provide a sound basis for the further development of vocational rehabilitation. The Act signed by the President on the 3rd of August, 1954, Public Law 565, 83rd Congress, continued the basic provision for services to handicapped people and in addition greatly broadened the scope of the program by authorizing a series of sweeping changes in professional, fiscal, and technical aspects. Of especial importance was a system of grants to state agencies to provide financial support to develop new aspects of their work and to extend it to disability groups heretofore inadequately served. Grants were also made to encourage and support research and to better rehabilitation methods and to conduct demonstration projects that would be useful in spreading new knowledge to communities throughout the country. The Act also provided stimulation of training of more professional personnel.

Today hundreds of facilities around the world are translating the philosophy of rehabilitation into daily action. Tremendous resources in personnel and money have been tapped to construct, equip, and operate these rehabilitation facilities. This movement is considered by many as an American contribution to the welfare of mankind. I have watched it for 45 years, from its early beginnings. I have seen how the nations of the world not only have made their individual contributions to the concept of rehabilitation but have now accepted the program as a commitment and moral responsibility to husband and maintain their human resources, thus epitomizing the words of the philosopher Paulsen who said, "The object of all help is to make help superfluous."

I said at the beginning that rehabilitation as a challenge to the problems of the physically handicapped held out a promise that has never been fulfilled. In the face of the excellent report of the Vocational Rehabilitation Administration with its record of 125,000 cases rehabilitated in 1964, with its plethora of demonstration, research, and training activities, this is a serious charge. But for all this activity, for all the money and power of government, for all the heart and dedication of professional and nonprofessional workers in the field, the results have fallen far short of even reasonable goals.

In the first place, the basic aim of rehabilitation services was to fit the disabled for remunerative employment. The record of 1964 with its 125,000 made employable was both a victory and a failure. It was a victory over the prejudice and apathy of the public. It was a victory over the confusion, the pessimism, and the despair of the physically handicapped. It was a victory in demonstrating, however limited, the practicability of this social measure for the utilization of manpower. It was a failure in that so small a number were rehabilitated compared to the 2,500,000 who needed these services. It was a failure in that it has broken only the strong outer defenses of tradition, with its cherished infamies, calumnies, and prejudices.

In the second place the ideal of integrated services to achieve full resettlement of the individual has not been realized. The many variables of psychological, social, and vocational adjustment have been beset by a gargantuan diversity of administrative, financial, political, and organizational problems. The pioneering efforts of Dr. Fred H. Albee to achieve such integration have been pursued by his many successors and disciples with only limited success.

Finally, the medical profession has observed the national rehabilitation scene with mixed feelings. The thousands upon thousands of patients who have been the beneficiaries of modern medical and surgical miracles have resumed their places in society without the assistance of psychological or social services and without the aid of public and private welfare agencies. The physician is well aware of the great biological factor of safety in human structure and function that permits them to overcome physical incapacity. These reserves are part of the homeostatic principle that permits "the natural disposition to restoration" so well described by John Hunter. Hence the physician is suspect of many of the paramedical and ancillary services that presume for themselves a divine omniscience in the role of the patient's recovery and resettlement. The physician is also conscious of the strong emotional component in illness and that motivation toward recovery is not a product of psychological, social, or psychiatric technics but of what the individual thinks of himself and of what society thinks of him.

Today we must re-examine the problem of the disabled not alone as a function of physical restoration, of vocational guidance, of independent living, or even of employment. It is now part of the greater problem of invalidity.

The determination of eligibility for either social security or rehabilitation services and the provisions for rehabilitation services or pensions now require a much broader study than we have given before. Where does the problem of invalidity belong, in social security, in public welfare, or in rehabilitation services? It is obvious that the next 10 years will bring newer interpretation and newer methods for meeting this problem. The roots of these answers have been developing in the past 45 years. Only refinement and readjustment to our changing political and social philosophy are needed.

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A Commitment to Service in Rehabilitation: A Statement of a Philosophy

ALICE M. TURIELLO

Summary

Maintaining a personal commitment to individuals with disabilities requires daily, realistic appraisal of available energies, faculties, and potential results. With this approach, rehabilitation workers can remain spirited and dedicated in the face of patient setbacks and professional opposition to their ideas.

Accepting the realities of daily living puts the rehabilitation professional in harmony with patients who must necessarily set their goals one day at a time. The understanding and acceptance shown a patient in despair may bring the comfort that will lead to a reaffirmed courage and a determined spirit.

A MAN'S PHILOSOPHY, if he follows it, guides his life into channels where he can best express what he believes. In the field of rehabilitation, where the focus is on the individuality of each person and his inherent worth, my philosophy involves: *1)* an awareness of the many factors influencing the way in which a man will react to his disability, *2)* a commitment to extend oneself in service to those in need of help; keeping in mind that each man is different and that his differences must be respected, and *3)* in my point of view, an enthusiasm and a love for one's fellow man.

Accepting the first part of my philosophy—knowledge and awareness of the intertwining factors working in rehabilitation, let's consider the second point involved in this philosophy—a commitment of one's self to the work chosen. I have just been reading *Experiments in Survival* and, as I put the book down, the thought comes to me what commitment really means. It is, for one thing, a realistic appraisal of a situation. No romantic notion of selfless devotion to a cause not fully comprehended will do. This realistic appraisal is followed by an earnest endeavor to do what can be done to make the situation better. There is no lifetime commitment made in a day, but rather a gathering, from day to day, of energies and faculties, which are focused on a central idea. To be committed is to each day offer that which is best in you to the task at hand. Tomorrow's services cannot be offered today, nor can what happened yesterday extend beyond the time that was yesterday's time.

Perhaps we are all aware of the highlights, the dramatic moments in our lives, when we feel a burst of enthusiasm, an ability to move mountains, a desire to go out and convince the world. Nothing is impossible to us in this state. If only everyone could see what we can see. But somehow this does not work. The people about us bring up problems, blocks, alternate ways, and reasons why our plans are not feasible. Reality comes back with a shock. The burst of enthusiasm fades. And we are left with the situation as it was. Now is the time when commitment, certainly not stated and perhaps not even realized, remains to keep us on the track, to go back again to the routine of the job, to continue working, and to continue hoping. No magic formula is available, and yet we cannot but feel that perhaps there is a magic in the very persistence with which we doggedly carry on.

Rehabilitation Literature, May, 1970—*Alice M. Turiello was a rehabilitation nurse employed by the Easter Seal Society of Massachusetts, Worcester, and assistant director of nursing in charge of service education at Peter Bent Brigham Hospital, Boston.*

The hopes of men and women who are seeking rehabilitation are an example to us. We may put our own hopes in their success. That is primarily what rehabilitation is. The whole elaborate complex of agencies, services, buildings, people, and things is not rehabilitation. Rehabilitation is the extending of a hand when a hand is needed, so that the first step, and the second step, and the third step may be taken. Until, finally, the hand is no longer required and the person can manage to take the steps on his own. It is then that commitment involves letting go of the hand, saluting the accomplishment and the independence of the person, and turning to the next one whose hand is extended in need. The real spirit that motivates this feeling exists in quite an ordinary setting. It is through the realities of living day by day that we build up a satisfaction in helping others to meet their days one at a time.

There is a special focus to commitment that involves not only the mind and the body in action, but the heart as well. There are those who can carry out a task with their hands and yet they are completely divorced from the task. Their minds and hearts are far from concerned. And, again, there are those whose minds are rapidly assessing alternative possibilities of action that may provide a suitable arrangement for a person, but they give no thought to what the person himself is thinking or feeling. Their hearts are not involved. They cannot appreciate with their feelings the struggle that may be going on in this man's life. A prayer attributed to St. Francis of Assisi, which I like very much, will help to emphasize the point.

Lord,
make me an instrument of Your peace.
Where there is hatred let me sow love;
Where there is injury, pardon;
Where there is doubt, faith;
Where there is despair, hope;
Where there is darkness, light; and
Where there is sadness, joy.
O divine Master,
grant that I may not so much
Seek to be consoled as to console;
To be understood as to understand;
To be loved as to love;
For it is in giving that we receive;
It is in pardoning that we are pardoned; and
It is in dying that we are born to eternal life.

Despair, darkness, and sadness fill the hearts of many who are severely disabled. The nurse may be able to offer at least a part of the consolation, understanding, and love that are effective in turning the despair to hope, the darkness to light, and the sadness to joy. Despair says that life has reached its limits of endurance. That there is no sense in trying any longer, for no efforts would be of avail. The darkness is the blackness of no way out—a tunnel whose opening is blocked from view. There are no words to convey the emptiness, the desolation, the total meaninglessness of life.

At such a time, love is the only answer that makes any sense. My brother needs me. I must comfort him by my acceptance, by my union with him in his sorrow. I cannot know its depths, nor can I appreciate its bitterness, and, yet, there is comfort in a presence that does not condemn, but only listens. The way back to a *living* life takes a determination and courage that may be fostered by knowing that someone does care, greatly.

The Issue of Theory in Rehabilitation

RICHARD E. HARDY, Ed.D.

Summary

A major weakness of rehabilitation is its dependence on methods and techniques not fully researched or subtantiated. When counselors repeatedly use unconfirmed hyphotheses, they subject their clients to mistakes because those hypotheses provide no basis for refining or modifying theory. Improved theoretical systems will sharpen evaluation of increasingly complex rehabilitation problems, outcomes, and procedures.

Depending excessively on daily observations reduces professionals' objectivity, obscuring the true contributions of counseling, evaluation, and placement. Continuing self-evaluation will clarify the need for an objective, scientific theoretical framework to increase efficiency and the ability to predict.

Rehabilitation Literature, June, 1971—*Richard E. Hardy was chairman of the Department of Rehabilitation Counseling, School of Community Services, Virginia Commonwealth University.*

REHABILITATION has as one of its major strengths the characteristic that it not only draws upon the theory and effective methods of practice developed by other disciplines but also develops its own theory and useful methods of practice. As one of its weaknesses, rehabilitation has the characteristic of continuing to practice methods and technics that have not been fully substantiated through research and lack congruence with any particular theory.[1]

Rehabilitationists often speak of their dislike or disinterest in theory. The statement is made that technic or practice is more important than theory. However, what many of these well-meaning persons have not thought about sufficiently is that everyone operates from some theoretical reference. It is a common misconception that theory exists in opposition to fact.[2] Theories that are confirmed do give us definite facts to use in problem-solving, while those that are not confirmed may be improved, rewritten, or discarded. In this way, theories tend to be self-correcting. The problem that many of us in rehabilitation have is that we are actually using unsubstantiated hypotheses as if they were proved. When unconfirmed hypotheses are used over and over by a rehabilitation counselor in his work with clients, similar mistakes are made over and over because these unconfirmed hypotheses provide no basis to refine and modify theory, and so we continue to function from an inadequate theoretical framework.

The reason behind the needed serious search for new or at least improved theoretical systems is the presence of so many unsolved problems. Existing theories help us tremendously but have not been sufficient in allowing us to predict rehabilitation outcomes with the efficiency we need. Perhaps it would be helpful to examine examples of maxims that we seem easily to accept at face value. Some of these have been scientifically investigated; others are just philosophic types of statements that tie in only partially to established theories.

For example, we frequently state, "It's ability not disability that counts," when actually the disability often completely dominates the individual's thinking and behavior and the reactions of others to him during his entire life. Generally, we accept the slogan, "Help the handicapped help themselves," as if this would apply across the board to all persons with all disabilities from every cultural system, when actually we know quite well that in the case of some severely handicapped persons very little self-help is possible.

At times we seem to accept the general assumption that man operates something like a computer. In other words, if he has certain information "pumped" into him, he will be able to solve many of his problems. We neglect to develop through counseling the self-actualization and creative aspects of our clients. We tend to place them at certain levels of employment rather than allow them to develop their own competencies to the fullest extent and secure employment in keeping with their abilities and goals. Hence, we find that some of the persons for whom we have provided rehabilitation services and closed "in employment" are now unemployed and maladjusted, with little faith in themselves or in rehabilitation. Maybe our ultimate goal in many cases should not be employment or work adjustment.

Often those of us in rehabilitation have achieved goals by the simple method of defining success in our own terms.[4] In the closing of large numbers of cases we have achieved considerable success by our own definition, but, as we all know, some of these persons who were rehabilitated have no real knowledge that they have ever been provided any substantial service from the rehabilitation agency. We hope these persons do not exist in large numbers. However, we know that they do exist, and we also know that a system that allows this to happen, with this procedure defined as "success," needs modifying.

Whitten[5] and Puth[4] have indicated that we professionals must take a more scientific approach to the evaluation of rehabilitation outcomes and procedures than we have in the past. One way we can achieve this as a group is through a basic understanding of the characteristics of a good theory. This understanding should lead to better individual approaches to testing the educated guesses (hypotheses) that we continually use throughout the rehabilitation process.

Rehabilitationists over the years have been characterized, and favorably so, as practical persons attempting to solve somewhat tangible problems. As the complexity of rehabilitation problems has increased, our approaches have become less useful. In other words, the more complex the problem, the more refined the procedure must be to solve it. Procedure must be developed from hypotheses that have been experimentally proved in rehabilitation settings. Rehabilitation professionals should understand that theories can serve as useful tools in the work of empirical investigation. Theories serve as guides, they sharpen our perceptions, and they help us to focus on the problem at hand.

In rehabilitation, we have witnessed a great deal of research on various aspects of the behavior of handicapped persons. Yet when one wishes to tie together findings, he is struck by the huge amount of what we might call "trait and factor" data that exist in an uncoordinated and disconnected body. Few rehabilitationists have sufficient time to tie these data together, and the result is that the theoretical side of our functional or practical approach is lagging; however, a good theory could help us use all of our data more systematically and effectively in order to improve our results—our ability to predict and our efficiency. This bears out the idea that there is nothing more practical than a good theory.[6] A theory should also be able to offer the ideas necessary to make relevant hypotheses. Such hypotheses can be verified or disproved after empirical data are studied and analyzed.[2] This process should aid us in the modification of our theory of rehabilitation and increase its usefulness across disciplines and cultures.

We may depend too much on everyday life observations. These are important in building the framework for the development of scientific approaches and for the development of what we might call initial theoretical formulations; however, without controls, those among us who are even the keenest observers cannot be counted upon to be objective. There is a great deal of ambiguity in rehabilitation because of its lack of scientific control. We are only moderately certain that, by having a client go through various rehabilitation states and procedures, he will be substantially helped in his own "adjustment." Of course, we need to define the term *adjustment* and this has to be evaluated individually for each client, but the point is clients might just rehabilitate themselves if left alone.

We need to study experimentally and verify statistically the effectiveness of many of the services offered to clients. We are not always certain, for instance, of the contributions of counseling, evaluation, and placement to "successful" rehabilitation outcomes. Frequently the goals of rehabilitation are vague and incomprehensible to our clients even though as professionals we profess their clarity. The goals of the client should be evaluated to determine whether or not his goals are congruent with those of rehabilitation. Again, we have no sure way of knowing if the clients' goals are satisfied or whether he could have achieved his goals without our intervention.

Another requirement of a theory is that constructs must have operational specificity.[2] If we define our clients as "the handicapped," "the blind," and "the deaf," we are automatically assuming that there are certain characteristics that always exist and that we can use in understanding the complex nature of individuals. We might also consider that this implies certainty and predictability. The use of such terms does not contribute clarity and explicitness, which are very important if the theory we hold is to be used by others without ambiguity. The classification "the blind" means very little to some of us, while to others it may have much more explicit meanings.

Human nature is highly complex and existing knowledge systems are at best only relative and probable. We need constantly to strive to increase our efficiency and our ability to predict. We need to reconsider our assumptions, define and redefine our terms, and clarify our hypotheses.[3] We must continue to study the internal relationships, the consistencies, and inconsistencies that exist within the knowledge system that we seem to be using, and, since our ideas, concepts, and knowledge systems are highly subjective, we need continually to evaluate ourselves as social scientists who are operating within set systems based mainly on our own values. A sincere self-evaluation will surely lead us to the search for a more useful and scientific system of theory development and problem-solving.

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The Problem of Personal Worth in The Physically Disabled Patient

H. JON GEIS, Ph.D.

Summary

Because feelings of self-worth are key to successful physical and emotional rehabilitation professionals need to understand the concept and implications of personal worth. Self-definition is rooted in basic values. Individuals do not feel worthwhile if they are incapable of fulfilling their own values. Clients in the initial stages of rehabilitation commonly see themselves outside their own value system and, consequently, they feel little self-worth.

Feelings of worthlessness emanate from unproductiveness and unattractiveness. By focusing on their deficits, many overlook their intrinsic worth, eventually concluding they should not exist. Therapy must change this self-defeating perception by convincing patients that their standards of productivity and attractiveness are not needs, but fixed beliefs preventing realistic achievements. Orienting clients toward "being" rather than "doing" behavior may stimulate greater self-satisfaction.

Rehabilitation Literature, February, 1972—*H. Jon Geis, Ph.D., was a clinical psychologist in private practice and director of training at the Institute for Advanced Study in Rational Psychotherapy, New York, N.Y.*

IN THE SPRING of 1963 I presented a convention paper on the subject of personal worth as a psychological problem in the rehabilitation of physically disabled patients. For the several years prior to this time I had worked intensively and exclusively with such patients at major rehabilitation centers in the New York City area and I had become convinced of the importance of this problem as it existed in the core of the psychodynamic blockages, which, I felt, held the key to the individual's successful physical and emotional rehabilitation.

Since 1963 I have been heavily engaged in a more than full-time private psychotherapy practice in which I have seen many hundreds of patients in a wide variety of diagnostic categories. I have found the problem of personal worth to be the central psychodynamic problem of all patients, not just those with physical disabilities, and I have spent a good deal of time developing technics and theory appropriate for its full consideration. This material, not appropriate for inclusion here, is presently being integrated into a lengthy consideration of counseling and psychotherapy for eventual presentation in book form.

However, in the years since 1963 I have had increasing misgivings about my failure to make my original convention paper available to a wider public, particularly to rehabilitation professionals. I have therefore decided to publish it. Although nine years have passed since it was written, it is my judgment that the material is more relevant and timely than ever. The passages that follow constitute, with the exception of some editorial changes, the same paper as that originally presented to an audience of professional rehabilitation workers at the 1963 convention.

The Person, Personal Worth, and Value

What is a person worth? This is a simple yet searching question. It is a question every man consciously directs toward himself at one time or another, in some form such as "Am I worth it?" or "Am I worthwhile?"

At times it is expressed in the negative: "I am worthless, no good, a nothing." More often the person is aware of his negative self-appraisal as a feeling of worthlessness or inadequacy, rather than a clear cognitive idea. Beyond these relatively conscious expressions, however, the sense of one's own worth, high or low, appears to be a relatively stable and ongoing aspect of one's identity or self-concept, lying for the most part out of awareness.

We might ask whether "worth" is really anything more than just another term that is used to stand for self-esteem or a related self-description, whether it is really a phenomenon in its own right and justifies inquiry. Many investigators apparently do not view self-worth as an important aspect of one's self-evaluation. In Wylie's[13] review of studies dealing with the self-concept there are only 2 studies dealing specifically with "self-worth" out of a list of approximately 480 references. However, to those who work closely with the physically disabled there is strong clinical evidence that the term is meaningful in its own right: Our rehabilitation centers and agencies are filled each day with persons who express in direct or hidden ways the feeling of being worthless. Depression, self-blame and self-hatred, blocked motivation, slowed behavior or pathological compensatory activity, and difficulties progressing on the rehabilitation program and in community adjustment—these are all concomitants of feelings of low worth. It therefore seems crucial that we, as professional helping persons in the rehabilitation field, try to understand the nature of the problem of personal worth and its implications for the distressed people with whom we work.

Let us begin by defining the term *worth*. English and English,[3] in their *Dictionary of Psychological and Psychoanalytical Terms,* define worth essentially as follows: "The value placed by a given person upon something." This tells us that worth has to do with value, for our purposes, the value a disabled person places upon himself. The logical aspect of our problem, then, falls within the scope of axiology, which is the scientific study of values and evaluation. The study of values has, of course, been pursued for thousands of years as a specialty within philosophy.

Our question now is: What does it mean when we say that a physically disabled patient values or does not value himself?

If something is of value it is a positive thing for us—that is, we have an approach valence regarding it—and it is so because it is actually or potentially capable of giving satisfaction to us. The physically disabled patient values himself positively, or feels worthwhile, when he perceives himself as giving or being capable of giving satisfaction to himself now or at some future time. Beyond the simple requirement that a thing be satisfying to us for it to be of value, the value problem gets more complex.

Here it is important to be aware of what is continually a controversy among value theorists, namely the location of values—whether value resides in the object valued (e.g., an automobile), in the object valued and also in the person doing the valuing (i.e., in the relationship between the automobile and the person), or only in the person doing the valuing.

Smith,[11] in his monograph on *Value Convictions and Higher Education,* warns against confusing the three locations and says that at any one time "value" may mean one or more of these: "Value may mean *what* is chosen, the fact *that* something is an object of choice and is preferred, and *why* it is chosen." The third location—the *why*—is value as it resides in the personality or in the character structure of the person; it is, as Smith refers to it, "a criterion or standard for decision-making." When we speak of a value in the personality we refer to a basic, emotionally embedded disposition of the person to behave in terms of some abstract concept of worth. A collection of these basic values may be referred to as a value orientation, as for example Erich Fromm's marketing orientation, Holland's[5] motoric orientation, or one's orientation toward oneself, often called the self-concept.

The first location, value residing in the object, is called a value preference when it is indicated as an object of value by the person. When a patient states a preference for himself, as, for example, when a paraplegic young man says he likes himself when he ambulates on crutches, he may say this because being on crutches makes him feel more independent, more powerful, or more attractive. That is, any one of a number of values in the patient's personality may account for the same value preference, liking oneself as a person who ambulates.

Smith's analysis is based on an examination of what he calls "the human capacity for evaluation" as it is represented in the act of valuing. He says[11] that "the ability to respond . . . in a critical way . . . is at the basis of all discussion concerning what has come to be called *value" (p. 8).* The critical response has three essential components: *a)* awareness of a contrast in experience, so that we may be able to say that one alternative is better than another; *b)* a criterion, or standard for decision-making, so that we may be able to make a judgment; *c)* relevant knowledge of the situation. The most important component of the critical response—the part that, for Smith, is value—is the criterion: "Unless the critical question is raised concerning the criterion of the preference or choice and its *binding force* upon us, we are as far from the center of value as we can be" *(p. 14). "For the value aspect resides in the criterion determining the critical response."*

Hartman[4] has made the same point in a different way. In asking how we know what is good, which is another way of talking about what is of positive value, he concludes that "Good is a property not of objects but of concepts. . . . whenever the word 'good' is used, a logical operation is performed: we combine the properties of the concept of the thing with the idea of the particular thing that is said to be good (of value). . . . This logical operation is the meaning of the word 'good' (or 'value'). . . . A thing is 'good' (of 'value') . . . if it has the qualities that define its concept." What Hartman is saying, in terms of our problem, is that the patient values himself to the extent that he fulfills his idea of the kind of person he should be. As we have seen earlier, this idea is rooted in one's basic value orientation toward oneself. Therefore, we may conclude, in agreement with the psychotherapy terminology of Ellis,[2] that it is the patient's definition of himself, as it is rooted in his basic value orientation toward himself, that allows him to feel of worth or of value to himself. If he basically defines himself as worthwhile or valuable to himself only when he fulfills his own values regarding the kind of person who is worthwhile and valuable—then he cannot feel worthwhile or valuable until he is that person.

Personal Worth Depends upon the Self-Definition

The paraplegic young man who focuses only on complete physical return, the once-beautiful actress who was disfigured by scalding water and continues to yearn for her former beauty, the teenage boy with the congenital limp who idealizes the normal physical status of his peers—these are people who continue to define their worth—that is, their value to themselves, in terms of a self-image that can never be, and necessarily, then, they cannot feel worthwhile. It is true, of course, that physical and social realities are ever-present reminders to the person that he is not getting and cannot get the same satisfactions from the environment and, hence, cannot give himself the same satisfactions that he was able to get with his former status. Yet the problem is still basically one of the individual's definition of himself, whatever the realistic opportunities for objective environmental benefits. The patient's definition of himself is the crucial factor determining in what ways he does or does not satisfy himself; that is, things outside of the patient do not satisfy the patient, but he satisfies himself in terms of these things. He is the arbiter of his satisfactions and he determines his satisfactions by the way he defines or conceives of himself.

It might be argued, for example, that the patient may be made to feel worthwhile if he is told that God loves him or if others act toward him as if he is worthwhile. From a technical point of view, sometimes these technics may work, but only if the patient first believes in God and defines himself in such a way that he values himself positively because he is loved by God. Similarly, he basically has to define himself as worthwhile because others treat him as worthwhile. His belief in the importance of being loved by God or being thought of as worthwhile by others permits him to feel satisfaction or, more correctly, to give himself satisfaction and thereby to value himself positively.

Let me pause a moment to note that the problems of value change have of course been dealt with by others in the rehabilitation field.[1] The present discussion is somewhat different, I think, because it focuses not only on the person as an object of his own value, but on the relationship between the notion of value and personal worth.

If, then, the patient's feelings of high or low worth, and the accompanying benefits and difficulties in adjustment, reality adaptation, and so on are contingent on his definition of himself, the problem is: What kind of definition of himself might the patient acquire so as not to feel worthless? Moreover, what can we do to help him toward a less self-defeating and more self-enhancing definition of himself?

To help us in thinking about ways to change the patient's self-definition, let us consider two other aspects of the personal worth experience, namely, the psychological meaning of feeling worthless and the problem of whether there is any such thing as intrinsic self-worth.

Our culture's great emphasis on the values of productivity and success on the one hand, and being attractive physically or in personality on the other, has been well documented by many writers. One might argue, with some success, I think, that any culture at least moderately encourages productivity and personal attractiveness because of the required nature of functioning in socially productive and esteemed roles—that is, as a worker and as "a person one would like to know." Our culture, however, emphasizes these goals so strongly that not to achieve them, or be on the way toward achieving them, tends to require feelings of worthlessness. These feelings are most dramatically noticeable in the traumatically injured patient whose ability to obtain satisfactions through productivity or attractiveness is suddenly cut off.

Operationally, as I have noted it in clinical work with patients, the basic ideational content, either openly expressed or thought, of feeling worthless as a result of the productivity value, appears to be: *a)* I cannot be productive now; *b)* I have always been unproductive; *c)* I always will be unproductive and life is hopeless for me; *d)* therefore, I am worthless and an awful person; *e)* and, therefore, I might as well not exist. For the beautiful actress who is now disfigured the thinking is similar: *a)* I am not attractive now; *b)* I have always been unattractive; *c)* I always will be unattractive; *d)* therefore, I am worthless and an awful person; *e)* and, therefore, I should not be living. Note here what is involved:

First, the patient's thinking that he cannot be productive or attractive now must undoubtedly be a distortion—there are very few cases where all of one's productivity or all of one's attractiveness is eliminated in all respects. A paraplegic may be productive in many ways and an actress may be attractive in figure, dress, personality, and other ways. Feelings of low worth, like self-esteem, depression, and some other emotions, tend to be all-or-none in nature. That is, the emotion may be evoked by consideration of only one aspect of what is most often a complex situation and the patient may feel, and conceive himself to be, "all" worthless. It is true that sometimes the attachment seems to be only to a particular aspect, such as productivity as a door-to-door salesman or attractiveness of face. But most often even these situations imply a general, more basic value orientation in terms of which assets related to productivity and attractiveness are still available. Here the notion of emphasis of new value areas, with consequent "value spread," as discussed by Wright,[12] is relevant.

Secondly, in our examples of the experience of feeling worthless, note that past and future time perspective is cut off or distorted: The patients are unable to conceive of themselves as ever having been productive or attractive in the past. They might provide themselves much satisfaction and feel more worthy in terms of what they did or were in the past, but they do not consider this. Further, they might derive satisfaction and worth from contemplation of possible changes in their condition in the future, that is, of their potential worth, but, similarly, they do not perceive this.

Third, the patients' conclusions, that they are worthless because they are unproductive or unattractive, in one sense are logically true because they are conclusions drawn from their arbitrary definitions of themselves. But this is a distortion because it assumes that worth is based only on the deficit feature, overlooking evidence about remaining assets and, perhaps, what might be called intrinsic worth. (I am worthwhile—I simply assert that I am—without the need to fulfill any conditions to be so.) Note also that the patients conclude that not only are they worthless but they are awful people, which implies that they expect rejection from other people and don't deserve anything else. Not only are they worthless but, to some extent, of negative value. Their thinking runs: "If I am not of value to myself, then I am not worth valuing, and others will reject me; that will be something terrible that I cannot stand. I must be an awful person." This kind of thinking may persist for long periods with great strength, and it may account for both withdrawal behavior and a frantic search for approval and love.

The last factor, where the patient feels that he should not exist, is a conclusion drawn from the patient's evaluation of himself as worth nothing, to himself or the world, and therefore his life is meaningless and empty. This is not to say that most or nearly all patients do not want to live, for I believe they do. However, the logical conclusion that the patient must draw from his irrational premises is that of ceasing to exist. I have seen this conclusion expressed at least partly in most patients, fully in many others, particularly soon after onset of the disability, and it is especially strong in those patients who have intense guilt feelings.

Intrinsic Worth—An Illusion?

Another important consideration is whether it is possible for one to value oneself intrinsically, that is, apart from any externally derived notion of what one should be. This notion is of course related to the concept of asset value, where a thing is valued for itself alone, versus comparative value, where a thing is valued according to whether it is better or worse than something else.[1] Here the object to be valued is the patient himself.

In general, people in our culture value themselves in extrinsic terms, that is, according to externally derived standards such as achievement, productivity, and attractiveness. As suggested earlier, intrinsic worth refers to the valuing of something simply in itself, without a criterion. Though desirable psychologically, this would appear to be an extremely difficult if not impossible goal to achieve in actuality. Perhaps it is a technical problem only. At this point I cannot be sure. But what it means is that the individual must be able to assert to himself that he is worthwhile or valuable without fulfilling any prior stipulated criterion. No conditions, no if's, and's, or but's—he simply is worthwhile. At present (1963) the technics for helping the patient achieve this state are, at best, unclear if not forever out of reach. For it does not appear possible for a person to value himself when there is no satisfaction-giving aspect of himself to value. On the other hand, it is hard to conceive of a patient who is completely unable to give himself satisfactions. But then this returns us to the framework of extrinsic or contingent value or worth. As we will see later on, I believe the psychology of Being may be employed to increase the patient's ability to get satisfactions from himself.

The Therapeutic Goal: Change the Self-Definition

Let us return now to the problem of changing the patient's self-definition from a self-defeating to a self-benefiting one. We have seen that the valuing aspect of the patient's definition of himself is anchored in his basic value orientation toward himself. Insofar as he yields himself satisfactions that meet his basic value standards, he values himself positively; when he does not, he tends to consider himself worthless or of negative value. The patient whose work productivity is limited by his recent disablement must learn to value productivity—or more correctly, to value himself as a productive person—as something desirable, preferred, and perhaps worth aspiring toward, but not as something necessary to his sense of worth. This is similar to the notion of asset value.

However, I think the therapeutic effort should be directed not only toward emphasizing the asset nature of the value, which seems to be the emphasis in the literature (e.g., B. A. Wright[12]), but it should also focus strongly on eliminating the need aspect of the value. That is, the patient should be taught, as Ellis suggests,[2] that he does not need or require fulfillment of his value orientation to live happily or to feel worthy. As Ellis points out, there are few if any things outside of the physiological needs that a person cannot do without, although he might not be as happy as he would be without these things as with them. The patient creates disturbance for himself when he believes—incorrectly—that he must produce at a certain level or that he must have an attractive face. He defines his situation so that he necessarily and inevitably feels worthless and an awful person because his requirement is fixed and absolute. Therapy involves showing the patient that he does not, actually, desperately need to attain a certain standard of productivity, that his dire need is really only a fixed belief, that this fixed belief necessarily causes him disturbance and prevents him from getting satisfactions that are attainable, and that he is better off valuing his goals, and thereby himself, preferentially rather than absolutely. When the patient learns to look at things this way his basic value orientation will have changed and he will have defined himself differently.

We should remember, I think, that often it is a good idea for a patient to retain high standards for himself. Maladaptation and poor adjustment are promoted not by high standards *per se*, but by rigid, unrealistic, requirement-centered adherence to these standards, an adherence that by its very nature must result in feelings of low worth and self-blame when the goals generated by these standards are not attained.

The Psychology of Being in Rehabilitation Work

In addition to what we have already discussed, there would appear to be on the horizon a whole new set of ways to increase the patient's self-worth and promote good psychological adjustment. Due to space limitations I can go into this area only briefly.

When we look at ourselves as rehabilitation workers and when we look at our professional literature, it appears that we are wholly preoccupied—often with as much intensity as our patients show—with helping the patient develop better ways of doing things; that is, to become more efficient at reaching goals (which is extrinsic valuing), rather than at least also setting out to help the patient learn simply to be, that is, to value things in themselves (which is intrinsic valuing). One notices no great emphasis in our field on technics to facilitate asset or intrinsic valuing. However, in the last few years American psychology has begun to devote some concern to the psychology of Being, as for example in the writings of May[6] and Maslow.[7] Operations for attaining the Being state are rather vague, but it seems high time that these notions be thought through and tested out for application in work with the physically disabled.

Florence Kluckhohn,[8] in her schema of valued personality types, characterizes Mexican society as having a dominant Being orientation and the American culture as stressing Doing. Being is described as nondevelopmental, almost spontaneous activity which stresses the "isness" of the personality. This kind of activity is found, for example, in *fiesta* activities. Kluckhohn's Doing orientation has as its more distinguishing feature "its demand for action in the sense of accomplishment and in accord with standards which are conceived as being external to the acting individual," which is exemplified by the stock American phrases "getting things done" and finding ways "to do something." Kluckhohn describes a third value orientation, Being-in-Becoming, which she characterizes as a kind of self-actualization or self-development, a spontaneous yet somewhat controlled kind of activity that is carried out in the service of development of the individual's total integrated personality.

Henry Murray's[9] analysis is similar to Kluckhohn's yet more precise. His ungoverned or process activity appears to correspond to pure Being, "a state in which the mind moves in its own inherent manner for its own intrinsic pleasure" *(p. 37)*. It is effortless and aimless, and marked by a continuous flow of ongoing activities. Close to Kluckhohn's Being-in-Becoming state is Murray's modal, or formal, activity. This, Murray notes, is closer to Being than to Doing. In modal activity satisfaction is concurrent with the activity. Illustrations are expressions and receptions of sensuous, dramatic, or comic patterns, such as ballet dancing and witnessing a ballet, or telling a funny story and laughing at it. A third type of activity, directional activity, corresponds to the Doing state, in that "satisfaction is linked with the ultimate effect (or goal) of the activity" *(p. 14)*.

Maslow distinguishes Being behavior from Deficiency-motivated behavior. Being behavior, he says, "is released . . . expressive rather than coping" *(p. 37)*, "non-striving, purposeless, self-validating" *(p. 68)*. Being behavior is valued for its own sake and is concerned with end-experiences and end-values rather than with the means to reach them. Deficiency-motivated behavior is goal-oriented, instrumental behavior that seems to correspond to the Doing behavior described earlier.

A heightened state of Being is probably one of the results of psychotherapy, even though few therapists besides May and the existentialists write about it as such. Ellis's talk about helping the individual to "be himself" and Rogers'[10] therapeutic goal of "an increasing openness to experience," or having a less defensive and inhibited personality, suggest an implicit emphasis on Being in psychotherapy goals.

But what, you may ask, does all this have to do with promoting the patient's sense of personal worth? Simply this: There is no doubt that two, perhaps three, modes of behavior have been distinguished: Being, Being-in-Becoming or Becoming, and Doing. The physically disabled patient's definition of himself and therefore his sense of worth have been based, in most instances, exclusively on values attached to Doing behavior. When the patient is as a result of his disability less able to provide himself with satisfactions in terms of the Doing orientation, his sense of worth may be increased by helping him to derive satisfactions, and thereby to value himself more highly, by increasing his ability to have Being experiences.

There is not enough space remaining for me to explore some technics for facilitating Being growth on the rehabilitation program. However, the following list of terms, which are aspects of the Being state, may stimulate you to think of your own technics for facilitating Being: exploring, manipulating, experiencing, being interested, choosing, delighting, enjoying, organizing, simplifying, being truthful and experiencing truth, being playful, being unique, and being realistic. With what technics, we might ask ourselves, could we increase our patients' capacities to behave in these ways?

In conclusion, I have tried to clarify the meaning of personal worth and to highlight it as a crucial problem in the rehabilitation of the physically disabled patient. I would hope that this paper has to some degree succeeded in these aims and that the related considerations will help to stimulate improved technics for dealing with it.

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Emotional Issues in Raising Handicapped Children

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Summary

Physicians' awareness of families' emotional reactions to the birth and raising of children with physical or mental disabilities can stabilize a stressed family coping with disappointment, guilt, rejection, isolation, and overprotection. Parents usually experience a series of responses to a child with disabilities. Those who withdraw from their child and their neighbors often retard the child's development more than the organic disability. Parents who deny the permanency of a disability may reject necessary diagnostic testing to avoid learning the truth.

Parents feeling guilty over their hostile feelings frequently transfer those feelings to their child and set the stage for never ending family resentment and turmoil. Healthy siblings, too, are subject to jealousy and resentment. A physician's compassion and timely intervention can help families cope with these distressing situations.

THE PHYSICIAN'S AWARENESS of how difficult it is to raise a handicapped child can greatly facilitate intervention at appropriate times. The physical aspects of disease are more successfully dealt with than are the emotional side effects. The majority of handicapped children do not become Helen Kellers. It is vital to note that handicapped people have tended to drop out of school early, have trouble finding jobs, and tend to lose jobs though objectively able to perform the work.[1]

The net effects of a child's deficiency on the entire family—and not just on the handicapped child—are adverse, though studies differ as to which areas of personality are affected.[2] Nor do we have any studies that specifically measure how much stress has been placed on these families. Among adoption agencies,[3] it is assumed that the parents of handicapped children are under stress, as such agencies do not place children in homes where a severely handicapped child is already living. The question arises: Can the psychological limitation of handicapped youngsters be traced to the parenting process?

I will discuss primarily two major groups—the physically handicapped and the mentally retarded. While there is some indication that life is more stressful for the families of the retarded, both groups share many common features. For example, there is at times a symbiosis between handicap and retardation, e.g., blind children because of the understimulation of one entire sense do not come close to achieving normal developmental rates—unless the mother is taught to stimulate the infant in nonvisual ways. It is also true in Down's syndrome that the severity of retardation stems not only from the genetic cause but from the quality of mothering (or lack of it in institutional care) during the first few years of life.

The parenting of children with purely emotional disturbance lies outside the scope of this paper. Emotional reactions to handicapping conditions obviously will share certain common emotional features, but

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some problems will stem uniquely from particular diseases. In addition, parents vary widely in the responses to such children because of their own varied backgrounds and personalities. Nevertheless, and despite hazards of generalization, this paper will focus mainly on what is common to emotional reactions in parenting a handicapped child.

Predictably, for a mother and father, the birth of a defective child provokes a storm of emotions. Both parents are overwhelmed by feelings of helplessness and disappointment, disbelief, anger, confusion, and guilt. The pediatrician's acceptance of these kinds of feeling—those not acceptable in our culture's stereotype of the good mother and father—will do much to aid rapport between physician and family.

During pregnancy mothers often worry about the possibility of having a defective child; yet in no way do these passing thoughts prepare mothers for the actual birth of a defective child. For a multitude of reasons it is painful. Children tend to be seen as an extension of the parents; hence, to bear a defective child is experienced by the parents as a personal failure. Solnit[4] likens the situation to a mourning reaction because during pregnancy the image of an expected child that most parents have in mind is a combination of desirable traits of the father, the mother, the grandparents, and so on. Anticipation based on these pleasant expectations is crushed when the child is born defective. Solnit feels that the pain in dealing with the loss of the normal child who was fantasied during months of gestation is essentially a grief reaction. Klein and Lindemann[5] have labeled the birth of a defective child as a family "crisis" because here, as in other crisis situations, disorganization follows the event and how the family resolves it will importantly determine how the family will function later on.

There are some indications that the flavor of the parental response may vary with socioeconomic class, that the mourning reaction is more evident in higher socioeconomic families and, hence, may be a culturebound phenomenon.[6] Perhaps in those families the higher preset expectations for the child produce a stronger reaction. In large families parental investment in any one child may be less and this can help dull the pain. But there are no families where the parents do not experience a tangle of emotions, and it takes time for the most normal of families to make a realistic adaptation.

How much time is enough or what the normal limits of time are we do not know. Often the younger pediatric housestaff expect instant acceptance. Even the six months referred to in psychiatric textbooks may be an illusion. This commonly accepted time period for readjusting one's life after severe trauma does not seem to apply in the present situation. Perhaps all traumas require a longer time for adaptation but, in the case of the handicapped child, the trauma is in a sense ongoing, as the physical presence of the child is a constant reminder of grief and loss.

Parental reactions to a handicapping condition that appears in any older child follows a course similar to that of response to birth of a defective child. The parents must relinquish the goals and fantasies they were attaching to a healthy child and must relate to a sick child—with a different and usually reduced set of expectations. The transition is not easy. There is, however, one major difference: When the child becomes handicapped later the parents have usually formed a strong attachment to the child; with the newborn the mother's emotional attachment to the child is still highly tenuous and is more easily arrested or interfered with.

The physician should be cognizant of this highly vulnerable relationship between mother and a newborn child and be as reassuring as possible when giving such medical information as need be given. I find that in this era when families tend to be informed of all possible consequences, restraint is required in the interest of the long-term development of the child. The mother-child attachment also can be disrupted when a handicapped child requires specialized medical care that physically isolates the child from the mother, e.g., when the baby is put in an isolette with all manner of tubes and equipment, the mother is deprived of the simple visceral satisfaction of holding her baby.

Recent studies[7] suggest that a lack of early physical contact between mother and child can retard the attachment behavior of a mother toward her child. As early as one month after a baby is discharged from the hospital, mothers whose contact with their infants was delayed—as compared to mothers with early infant contact—showed less attachment behavior. They did less looking at the infant, smiling at the baby, and fondling him. This lack of needed early physical contact has been hypothesized as the reason that so many premature infants are later hospitalized for failure to thrive. Similarly, battered children are more likely to have been premature or to have had serious illness at birth.[8]

One immediate response to the emotional impact of parenting a handicapped child is to withdraw from the child or reject him. Children with Apert's syndrome have often landed in institutions for the retarded. Experts on birth defects[9] now show considerable suspicion that these children are not in fact organically retarded but may come to function that way because of massive rejection by parents during the formative period. This possibility accords with the known effects of maternal deprivation based on the studies of Spitz,[10] Goldfarb,[11] and Yarrow.[12] In the case of Apert's syndrome, massive rejection is felt to be due to the infant's ugly appearance. At some medical centers the plastic surgeons are attempting early surgery to reconstruct the appearance of the baby's face and limbs, hoping to encourage acceptance of the child by the family.

Not all severely deformed children are rejected by their parents. One such child—among the worst I have seen—had a grossly deformed face, which included everted eyelids and mandibular hypoplasia, and lobster-claw deformity of hands and feet. But her parents were warm and responsive to her and played with her, using games and books appropriate to her age. The only thing unusual was the mother's refusal to allow nurse's aides to care for her child. The mother seemed to sense and fear the average person's reaction to her child's deformities and was trying to shield the child from that. Later she admitted her dread of taking the child to kindergarten the following year.

The importance of visibility of a defect cannot be stressed enough. If it is visible, we more readily tend to perceive a child as handicapped. To label someone as handicapped also has emotional implications, which include stereotyping and fixed attitudes by almost everyone—including parents. An achondroplastic person's main handicap is his small stature. Culturally, small stature is held in lower social esteem than is phenomenal height. Giants, though abnormal in the opposite direction, do not suffer as much social rejection as do midgets. A visible handicap is simply harder to deny and, thus, harder to avoid reacting to emotionally. It is more apt to provoke visible curiosity in public and also withdrawal.

A young child often reacts to the sight of a handicapped person by asking, "Why can't that boy walk?" or "Why does that girl look funny?" The parent, often uncomfortable himself, will usually tell his child to be quiet and perhaps add, "It's not polite to ask such questions." Parents of the handicapped child often feel ashamed under public scrutiny. In collusion with the adult community's reluctance to see handicapped people, they choose social withdrawal for both themselves and their handicapped child. The pediatrician who has good rapport with parents can help fight the common tendency for social withdrawal.

After the initial shock, parents often try to deny that the handicap signifies permanent loss. They may comment that the child will "outgrow" it, that "a cure will be found," or that the child will be all right "once he's home." This kind of denial may be a stage in the parental adjustment or may be a lifelong attitude. There are those who argue[13] that some parental denial is necessary to assuage the chronic sorrow of the parents and, in one sense, may be adaptive to a certain degree. Denial in its more blatant forms over a long period of time tends to interfere with good medical management and to hinder psychological adaptation by both parents and child.

I recall one mother who could not bear the thought of her child's having a congenital heart disease. After bringing her daughter to a major teaching hospital for a work-up, she removed the child against medical advice just prior to a final definitive study. This pattern was repeated when the child was admitted to the University of Michigan for another work-up but was suddenly discharged against medical advice just before the final studies were to be done. The last I knew of the case was that the mother had admitted her child to a third medical center. Certainly one would hope that the mother got help in working through her feelings before further cardiac function studies of the child were attempted. At any rate, my example is one of many variations on how denial can work against good medical management.

Parents with a handicapped child find it difficult to express their anger directly to the child. This makes discipline a problem because usually it entails a measure of anger, but to direct anger and aggression toward a handicapped person evokes tremendous feelings of guilt in every one of us. We all tend to act peculiarly toward handicapped people and to cloak any feelings of anger we have. In this sense the parents of the handicapped child are not unique—they simply experience the conflict more intensely. This is an area where the physician may be helpful to parents.

All parents, whether of normal or of handicapped children, face the occasional wish that their child did not exist. Such feelings can be dealt with when they are fleeting. But where the wish occurs frequently and with intensity, the parents are apt to suffer intense guilt. Handicapped children, because they make more demands on their parents and offer fewer rewards, can at times produce even angrier feelings than parents would normally feel. The parental feelings of anger at all the extra burdens, their irritation with the child's relentless demands, the subsequent guilt they feel at their own anger and hostility toward the helpless child—all these can be devastating for family life.

Often the child senses the resentment and guilt of the parents and uses it to pressure the parents into complying with still more of his demands. Then the stage is set for a vicious cycle of resentment, guilt, and then overprotection. More generally, parents adopt strong defenses to keep their anger in check.

Of the various parental postures, that of overprotecting the handicapped child is highly common. The child is overprotected both in comparison as to how much more attention he gets than is given his siblings and as to how much more he receives than is needed in terms of his handicap. This particular stance by parents is a stubborn barrier to the physical and emotional rehabilitation of such children. The problems bred by overprotection are many and varied. For example, in our hospital physicians and physical therapists sometimes find that a new level of motor functioning cannot be reached without hospitalizing the child and in effect doing a "parentectomy." The frequent description of the handicapped child as being excessively passive and immature seems to correlate with parental overprotection.

Precisely because overprotection is such an issue, it is important to understand what lies behind it. Most obviously parents are helped to deny their feelings of anger, resentment, and guilt by behaving as if they felt just the opposite emotions. Parents also are spared the pain of watching a child struggle with his limited capabilities, while they are once again being reminded that the limitations exist. And finally overprotection allows the parents to "make up" to the child for his disability—a need that springs in part from the parents' sense of guilt at having "given" the child a defective endowment.

Overprotection, thus, serves many purposes. It is deeply intertwined with the creating of a relative isolation for both parents and child. Parents of chronically ill children tend to retreat from relationships with their neighbors,[8] seldom take their handicapped children on vacations or outings,[14] and tend to discourage any socializing by the handicapped son or daughter. This compounds the problem, since the relative isolation of these families affords little chance for much needed dilution of ambivalent feelings. Directly restricting the handicapped child's access to social interchange further limits the child and adds another source of resentment for parents that they must cloak.

Such parents tend to be isolated not only from the community but within their own families. Linder,[15] who did group work with parents of handicapped children, found that virtually all women reported that the topic of the child's disability was not talked of at home! Nor does the silence stop there. Parents of a handicapped child show considerable reluctance to discuss the defect with the grandparents. Yet perhaps the most critical silence is that between husband and wife. Here the toll is evident from the higher rate of disrupted marriages in families with handicapped children.[8] Where the marriage remains intact, there is a tendency for the fathers to isolate themselves from the home[16] and the mothers to isolate themselves with the children. Of course, this pattern, although not unique to families with a handicapped child, must be an added deprivation for marital relationships already under stress.

One aspect of parenting a handicapped child that can afford parents a sense of accomplishment is their drive to inform themselves fully about the child's handicap and to provide the child with a setting that maximizes his chances to grow and develop. Sometimes benevolent circumstances occur under strange conditions. One adolescent girl's history included developing epilepsy at an early age, experiencing in midchildhood the trauma of her mother's death, and being institutionalized for four years at a state hospital. However, when her father's mistress moved into the home, she was enabled to achieve new and higher levels of learning and socialization. This woman sensed the handicapped adolescent's need for her and gave the girl a remarkably balanced feeling of protection and care, at the same time stimulating the girl to new achievements.

Selma Fraiberg[17] has demonstrated that an educator, without entering deeply into parental neuroses, can show parents by example how they, through playing with their blind infants, can increase the babies' repertoire of skills. Parents of children with cerebral palsy should recognize the necessity of putting toys where the young child can reach them himself[16] (an obvious point frequently ignored). Somehow the parents need to stand in the child's shoes and see what the world looks like to him, at the same time being objective enough to perceive what the child needs for his growth and development.

Adolescence for the normal youngster means bodily changes that force an awareness of sexuality in both parents and child. Even if the parents are no help to the adolescent with his sexual turmoil, peer feedback and support have immense value. The handicapped adolescent, being isolated, will lack peer relationships. In addition, the handicap of physical appearance will pose barriers to reaching mature sexuality. Too often these drawbacks are heightened by parental attitudes. During group discussions[18] with mothers of offspring having cerebral palsy, the mothers were quite negative about expressions of sexual feelings by their adolescents and were ambivalent about eventual marriage. Here the parental stance of being overprotective and of keeping the handicapped a "child" is meant to keep him essentially asexual. It is interesting, therefore, that the handicapped adolescents in their own group discussions moved far more quickly to issues of sexuality than did the parents. Since many parents, even of normal children, show discomfort around sexual matters, it is not surprising that the parents of handicapped adolescents find it difficult. Questions about sex are rarely put directly but are alluded to in vague, amorphous terms. The physician who is comfortable himself about discussing sexual matters can be of enormous help in both giving information to and counseling the handicapped adolescent and his parents.

Sometimes the question of whether to keep the handicapped child in the home arises at birth, sometimes at critical stages of growth later on. Formerly if a newborn was obviously defective at birth, the physician would recommend—would often insist—that the baby not be viewed by the parents but be institutionalized at once. It is now recognized that parental fantasies about the defective child may be far worse than reality and that for parents to see their defective child can actually be of emotional help. Clearly none but the parents can make this decision, particularly in cases of severe deformity. Physicians of an earlier day who insisted on rapid institutionalization avoided facing their own feelings about handicaps and were instinctively aware that it is somewhat easier to institutionalize a child at birth before the child is deeply attached to his parents.

Today, most physicians encourage mothers to care for their handicapped children at home, especially until a child is six years old, since a child's development at home is generally superior to that in an institution. In fact, some states require the child to stay at home until age five or six, or he is virtually forced to do so because the waiting list for the institution is five to six years long. For some families this creates severe hardship. If the question of institutionalization is raised when the child has grown older, the parents must face their feelings—not only about having a defective child—but all the myriad feelings engendered in the raising of the child. It is not surprising that parental reactions to institutionalization are heavily charged. Old ambivalences are reawakened and threaten them with the fearful question, "Am I rejecting my child?" or more commonly, "How can I put my child away?" Families often struggle for years with their guilt, fears, and anxieties before making a final decision.

If the family decides to institutionalize the child, certain realities other than emotional factors tend to influence the timing of the placement. The degree of the handicap is important. Thus, the more severely damaged children tend to be placed in institutions sooner. A second factor is age, e.g., it is easier to give physical care to a young child than to an older, larger adolescent. In addition, though it is rarely talked about, one suspects that the adolescent's sexuality plays a role in the timing of institutionalization.

Though my focus here has been on parenting, the effects on siblings of a handicapped child is an inseparable issue. Most parents of handicapped children have normal children as well. Clinicians, however, know that all too often parents direct most of their energy and attention to the handicapped child, to the exclusion of the rest of the children. As a child psychiatrist, I have frequently seen siblings of handicapped children with emotional problems more severe than that of the handicapped youngsters themselves. Often, too, research on the impact that handicapped children have on siblings emotionally is skewed by the researcher's bias, that is, researchers tend to have strong personal feelings about whether handicapped children should remain at home or be institutionalized, which in turn tends to cast suspicion on their very research or on the data itself.

Grossman[10] reported that some siblings in her study appeared to have benefited from having a handicapped sibling, since as college students they seemed to be more tolerant, compassionate, and aware of prejudice than other young adults their age. I would question whether the decision of the students to train for a helping profession was simply a matter of maturity or compassion, but whether it could also represent overcompensation for pervasive feelings of guilt or hostility, or both. There were not enough data to document either position. Other siblings in the Grossman study were reported to be damaged—bitterly resentful of the family's situation, feeling angry and deprived themselves. In some families, the larger burden falls to the oldest daughter, who is asked prematurely to accept many of her mother's responsibilities.

In my own clinical work, I am often confronted with a retarded child's sibling whose problem stems from the parents' meeting the burdens of raising the retardate at the cost of time and attention needed by the remaining children. In the current swing away from total institutional care for the retarded child in favor of retaining the child at home with community support, we may veer to another irrational extreme before the communities have developed more adequate support. I refer, for example, to support such as day care centers, which can also give short-term residential care during emergencies and vacations, and to counseling services.

In summary, the task of coping with a handicapped child in the home is highly complex. This makes it imperative, in deciding to rear such a child, that the entire family be helped, from the birth of the child onward, to assess their ability to manage so inherently stressful a situation.

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Sexuality and the Handicapped

MILTON DIAMOND, Ph.D.

Summary

Rehabilitation clients, professionals and their agencies, the client's family, and the client's partner cope differently with public and private sexual expression. Shyness and embarrassment may inhibit clients from discussing sexuality with a professional who is often untrained in sexuality and just as uncomfortable discussing it as the client. Agencies that focus on vocational placement or families which feel awkward about affectionate displays frequently ignore sexual issues. Partners of individuals with disabilities often turn to others for advice rather than their own partners. Solutions require realigned performance expectations, respect for individual choice, and open discussion of sexual options. A dialogue among five clients and their physician illustrates how a lack of guilt reduces the gap between expectations and capabilites.

PROFESSIONAL RECOGNITION of the sexual problems and concerns of the handicapped has been developing and expanding for the last several years. To date, however, little has been formalized in print and what has been done is primarily directed toward making the professional aware of the area as one of legitimate concern. For this presentation, I would like to formalize some specific matters to be considered, offer specific recommendations for handling problems, and develop a directness with dealing with some of the more controversial issues involved. This is now appropriate, since during the past several years many excellent people have contributed their knowledge and efforts to make the sexual problems of the handicapped a respectable issue of concern and have awakened many to the disrespect that must be attached to ignorance and nonconcern with the subject (e.g., Comarr; Gochros and Schultz; Kempton). These positive efforts have further engendered a desire for professionals to have working models and ideas to follow the general attitudinal changes stressed previously.

My presentation will be divided into several portions. First, I will indicate how the perspective of various individuals or groups color the way this subject is treated. Then I will deal with some specific problems and issues in sexual expression and follow this with recommendations for handling problems that fall into associated areas. My concluding comments will contain several general rules for improving sexual functioning that are pertinent for all, able-bodied and handicapped, but more so for the handicapped.

FIRST, I would like to make clear just how many levels I think are involved with sexuality and how these must be distinguished. It must be understood that when one considers sexuality, one must not think only of genitals or bedroom activity, although that is usually what first comes to mind. At least two broad areas must be considered: public and private sexuality.

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Public. How does the person act in public; what role is played by these actions? Will a handicap interfere with the individual's personal or public appraisal of his or her masculinity or femininity? For example, can a telephone lineman with a paralyzed leg accept, without loss of masculinity, the job of a telephone operator? Can the arthritic housewife accept the loss of her hands and deft touch without considering it a reflection of her femininity?

Sexual patterns and roles are our public demonstration of socially recognized sexual expressions. Public concerns may manifest themselves in the choice of how the individuals interact with society.

Private. Here we refer to the genital sexual responses and those inner problems not usually discernible. This includes the ability to maintain an erection, have orgasm, receive and give genital and sensual pleasures, and reduce sexual tensions in oneself or partner.

Naturally, these public and private concerns might be combined.

NEXT, I would like to make clear that we must not confuse genital satisfaction, love, reproduction, and marriage. These four areas are quite distinct, although they may go together or be related. We must clearly keep them separate in our own minds and in the minds of our clients, certainly to insure just what is being communicated. The four areas of genital satisfaction, love, reproduction, and marriage offer different rewards and present different problems. For example, a client wanting genital satisfaction doesn't necessarily want marriage and one wanting marriage doesn't necessarily want children or sex. If this seems like too radical a concept, just recall that it is only a few generations back when our ancestors had marriages that were arranged so sex and marriage were started without love, most present-day marriages are not entered into by virgins, and birth control and family planning are facts of life. In a very practical vein, we must insure that children are to be considered on their own merits not as visual proof of masculine or feminine abilities; reproduction is not sexual identity and neither is genital gratification. A handicapped person might be more disadvantaged than an able-bodied person in having a child who is not wanted for himself but rather as an affirmation of masculinity or femininity.

It is appropriate here to distinguish between the different stages during which persons may become handicapped. These may be considered: prepubertal, adolescent, marriageable, married, separated, divorced, widowed, and senescent. A teenager is obviously involved with different concerns than is a senior citizen and obviously the attendant concerns of one with memories of the past and lost demonstrated abilities would differ from those of one who never had experiences to draw from. While this will not be dealt with in detail now, it is well to reflect on how each stage has its specific concerns.

Perspectives and Issues

At least five different perspectives have to be considered in any professional situation. These viewpoints are those of: *1)* the client; *2)* the professional dealing with the client; *3)* the agency represented by the professional; *4)* the family in which the client resides; and *5)* the "second person" involved, i.e., the individual to whom the client's attention is or might be focused.

These five different perspectives all have a similar focus but they may differ quite markedly. There may even be many areas of wide disagreement and friction among these five factions although theoretically they should all be working together.

Client

The client generally looks at his or her problem as quite personal and private. The client may consider the sexual situation as separate from the handicap or part of the handicap but generally thinks it's a problem to be borne in silence and one that should not concern the professional. This is doubly so for the handicapped compared to the able-bodied. Both the able-bodied and handicapped have, first of all, been taught that sexual matters are private and not to be honestly discussed, so this is a common problem. But the handicapped also has or is given the feeling that any interest or effort that doesn't focus most directly on the handicap should be considered minor. For example, the blind should worry only about seeing and the paralyzed only about walking.

Professional

The professional quite often looks at sexual problems as outside both the professional's scope and the client's area of legitimate concern. The professional's training has generally been toward getting the individual back on the job, capable of caring for a family and generally self-supporting. Regardless of whether the professional has been trained as a physician, psychologist, social worker, or other type of therapist, until quite recently sexual counseling was never considered as within the legitimate scope of activities. Therapists were not taught the clues to which to attend in this area. Often, even if the client does bring up concern regarding the subject, the professional quite often avoids the issue entirely by not replying to the clues or defends himself by saying words to the effect of, "You should be worried about not being able to walk or not being able to see or not being able to hear rather than worrying about your sexual concerns." It's as if the sexual concerns have to be of lower magnitude than the other abilities. The professional more than anyone must realize that meeting an individual's sexual concerns can go a long way in reestablishing or establishing a general feeling of self-worth conducive to general rehabilitation.

It must be mentioned here, in contrast with what I've just said, that an overzealous professional should in this area, as in others for which he has been trained, be careful to be attuned to client sensitivities. One should not project concerns on patients that are not there, since many handicapped handle their sexual concerns quite well.

Agency

Agencies, most often, are interested only in those factors that they consider leading to job placement or getting the person functioning in the home. They think in terms of productivity or income and their distance from the client makes them even less aware than the professional counselor of some of the human sexual concerns of the client. Agencies change even more slowly than do individual professionals. So, even though the professional (physician, social worker, counselor, or psychologist) might be interested in the individual client's sexual abilities, the agency frequently takes a dim view of these concerns. Often, the agency is most concerned with image and thinks that being concerned with an individual's sexual problems is inappropriate for a state, foundation-supported, or religion-affiliated organization. Again, I think these views are changing and it's slowly becoming apparent, to both the professional and the agency, that, once an individual's worth as a complete person is re-established, he or she is much more apt to be educable, hirable, and self-content with himself and his situation.

Family

Next, we have the family perspective. Here the issue is quite different. To be sure, the family, too, thinks the sexual problems are private and not to be discussed in public. They think they are also outside the province of the agency or professional dealing with the client, yet the family is quite often ambivalent about the situation. While they recognize that these are valid issues, they generally wish the sexual concerns to be ignored; they want them to sort of "go away," since they are ill at ease dealing with them and don't really know how to handle the issues. They, too, are beset with the societal value that sex is private and not to be discussed in public.

Quite often, the family would imagine that if, especially in younger people, sex is not discussed, it would never come up in a person's experiences. As with the able-bodied, they don't know how to deal with overt sex, whether it be masturbation or displays of affection toward possible sexual partners. They have strong conflicts. On the one hand, they want to consider the handicapped family member like everyone else and thus allow all opportunities. On the other hand, they don't want to, as they consider it, raise false expectations and hopes. Lastly, it is difficult for the family to recognize that children or parents can be sexual. Regardless of age, elderly parents are often considered "beyond it" and children "not yet ready."

Second Person

Last is the "second person." This is the perspective of the one on whom the client focuses his or her sexual attention. This is also considered to be personal and private, but here the individual definitely is concerned with how the handicap may be involved, although the concern may not be shown. There is the question of just what the partner can do or not do and can this be discussed openly or will the issue be too sensitive for probing? Often both of the parties involved seek advice and counsel from others, lay and professional, instead of speaking with each other about sexual feelings, concerns, capabilities, and expectations.

Specific Issues

With my broad introduction and talk of perspectives, I will now present three specific issues that must and can be dealt with within these perspectives. These issues are: *1*) performance and expectations, *2*) guilt, and *3*) communication. While my remarks are directed mainly toward dealing with the concerns of the handicapped, it will be obvious that they apply equally as well to the able-bodied.

Performance and Expectations

Too many individuals view their sexual expression as a performance to be rated and graded on some sort of consensually agreed upon scale. It is as if there were a "right" and a "wrong" way to be sexual and anything less than "right" is to be criticized. Our society certainly fosters these expectations and we live with them in Archie Bunker fashion everyday. For our clients, in a realistic and nonjudgmental manner, we have to realign the performance expectations with performance capabilities, so that the only allowable criteria for concern are based on what the couple or the individuals prefer within their abilities. The capabilities naturally will limit the expectations, but it must be made clear that the value systems that an individual puts on a particular type of love relation, or sexual relation, or reproduction relation, or marriage relationship, should be on an individual level or a couple level, so long as public society is not disturbed. Private acts have no standards that are immutable or written in stone. As we ourselves don't ask society's blessings on our private activities, let's help our clients to be encouraged in arriving at their own acceptable solutions with our blessings. Not only should we sanction their solutions, regardless of how novel, but we must encourage experimentation so that many possibilities are attempted to achieve a maximum of satisfaction.

Guilt

Here it is appropriate to introduce the issue of guilt. Too often the clients have enough problems with considering themselves different. In the area of sexuality, we must honestly stress that being different may be of small actual matter, because what one does in the privacy of the bedroom is of concern only to the individuals involved. If the function of sexual expression is private genital satisfaction, then that takes precedence over public approval and, if the purpose is to give or receive love, then that is not dependent upon certain formulas of performance or public acceptance.

With these concepts, the client should realize that guilt is an inappropriate feeling, not because the individual is less able, but because no standards for anyone, able-bodied or not, are legitimately imposed. One needn't worry about being different sexually because anything goes that is functional and mutually acceptable. Oral-genital stimulation, manual stimulation, anything that the couple or the individual can find satisfaction in doing is okay and we as professionals and agencies have to make our permission and sanction (because we have the power to grant such) very clear. We must not put a negative value on any practice found acceptable, whether it involves masturbation, oral-genital relations, a female superior position, or anything else that satisfies the couple.

For this we have to train ourselves against being judgmental and considering some practices preferable to others. This doesn't mean that we have to force on any client any practice he or she may find objectionable. We also shouldn't force our own or society's guilt-laden values on the person or couple. We may encourage experimentation into previously personal or societally taboo areas. We should do all we can to help remove whatever inappropriate guilt feelings may exist in the achievement of sexual satisfaction.

Communication

Lastly, here it is appropriate to talk about communication. There are practically no sexual concerns or situations that cannot benefit from increased communication by and between the individuals involved. Expectations and performance capabilities can be more realistically appraised with good communication and false impressions can be minimized. The handicapped, as do many able-bodied, often attach a magnified value to certain suspected deficiencies without ever testing the reality of the situation with the "second person." For example, in the realm of sexuality, most of us are concerned with something in our physical makeup. In this regard the handicapped and able-bodied again are alike. Consider that an individual may be concerned personally with being bald, having small breasts, or being deaf, blind, or elderly. Only by communication with the "second party" can one find out if the concern is mutual or the magnitude of the concern. Communication between the individuals involved will reduce hesitancy in finding out just what is and is not possible and what is or is not acceptable.

As professionals, we must thus encourage open, frank discussions of sexual matters as legitimate topics of conversation (often this means removing guilt in talking about sex). We must realize, parenthetically, that communication may be nonverbal as well as verbal. A touch, glance, smile, or grimace may speak loudly. However, for most, an adequate vocabulary still provides the best means of transmitting ideas and feelings. Regrettably, not everyone has an adequate vocabulary and we as professionals may help in providing one. For the deaf, for example, we might remedy the lack in acceptable universal signs for many sexual and reproductive ideas. We hope a satisfactory vocabulary is available soon.

WE then come full circle. Good communication can help the other issues, linking performance and expectations and reducing guilt as well as helping in its own way. With this brief introduction, I'd like to present a dialogue and see how it exemplifies some of the issues at hand.*

JERRY: Well, I don't really think that I had any idea that things were going to be so different after the operation on my back. I thought my sexual life was going to be the same as it always was and it turned out to be completely different.

MICKIE: I think at first I felt a sense of desolation that the emotional side of my life was all over with and that I've been condemned to the life of a robot or a zombie.

FRANCIS: I feel embarrassed when I talk to girls because I drool a lot and I spit when I talk. And during the conversation, I keep on drooling; I feel like a waterfall.

GEORGE: A heart attack is a massive insult to the body, and to myself as a person. And because of this, the relationship between myself and others—the alienation, the depression—is a whole area of related phenomena that we ought to study very carefully; an area of which we know very little about.

BILL: I've been paralyzed for over 20 years and it's been so long ago that I've forgotten what "normal" sex was. But as I recall, it had to do with sex being pretty much equated with an orgasm. But since I've been paralyzed

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*At the 1973 regional National Rehabilitation Association conference in Hawaii, a half-hour video recording of various participants discussing sex and the handicapped, made with the aid of the Rehabilitation Association of Hawaii, was presented. This dialogue is a slightly modified portion of the tape. A full copy of the tape is available from the Public Television Library, 512 E. 17th St., Bloomington, Ind. 47401, under the title ***When Illness Strikes, Program 21*** of the ***Human Sexuality Series***, moderated by Dr. Milton Diamond.

and had a few chances for sex, I've realized that orgasm is not so important in sex; in fact, it actually hinders the enjoyment of it because when you don't worry about the orgasm and don't think about the orgasm, sex just continues on and on and it's never over.

DR. DIAMOND: When we think of the functions that sex serves, we have to think in terms of giving and getting pleasure, of reducing tension, of sharing intimacies. If we keep that in mind we can remove ourself from the stereotype that "good" sex involves only an erect penis in a vagina; that that's the only way or right way. Do you feel that the value of an orgasm is part of the myth Bill?

BILL: Well, very much so. In fact, before you kinda work up to something, and then it's over. This way, you just keep going on and on.

DR. DIAMOND: What do you find the most pleasurable thing now?

BILL: Well, still touching the penis, but just touching the nipples and breasts and the sides. I'm very sensitive under the arms.

DR. DIAMOND: So you could find your own way of giving and getting pleasure and that solves your own needs.

BILL: Yeah, but it's much better when somebody else does it.

DR. DIAMOND: Well, that's what I assumed.

BILL: You just have to try—find the right partner and I guess the right partner is just about anyone who shares your feelings toward each other.

DR. DIAMOND: Mickie, how about yourself?

MICKIE: Well, since being paralyzed and getting out of the more severe part of it, I find that I am perfectly normal except that the mechanics of the thing are different. My legs and back are totally paralyzed. As far as feelings are concerned, if anything, they're heightened because the type of polio I had made me hypersensitive. I find that it's just mostly the mechanics that interfere. And, of course, the preconceived idea that, because you're in a wheelchair, "Don't bother with her—she can't do anything anyway."

DR. DIAMOND: Well, we find that even able-bodied persons begin to find that there is more than one way to skin a cat and probably the handicapped find this out a lot quicker. George, how about you and your heart condition?

GEORGE: Well, I feel like there isn't that comfort that I'm getting from the rest of the people here about my relationship with sexuality. When I had my heart attack, the doctor told me to stop having sex for awhile but he never told me when to come on again. I feel a profound kind of lack of knowledge and hesitancy . . .

MICKIE: George, do you feel a sense of fear in this area?

GEORGE: Oh, yeah. I think that the fear that accompanies this kind of activity is very profound because it's a deep insult to the body. There's a great hesitancy and I think this leaves a feeling of separation.

DR. DIAMOND: How about with your wife? Obviously, you can look at it both ways. You may want love but she doesn't want to lose you. Francis, how about yourself with cerebral palsy? How do you see your condition now?

FRANCIS: Well, I'd like to be like any normal guy. I had this cerebral palsy since back in my preschool years. There came a time when the doctors over there wanted me to progress and I didn't progress rapidly. Now, I could do almost anything any normal person could do.

DR. DIAMOND: But now, are you dating now? Are you married now?

FRANCIS: Oh, no. I'm still dating girls.

DR. DIAMOND: Jerry, how about yourself with your back condition?

JERRY: With me, it was a problem, I believe, of creating a new self-image. I thought that I had to be the virile male and live up to my wife's expectations (which she didn't have) of me. She was perfectly satisfied with what I was able to give her after the accident but I was always trying to do more, and finally I just sat back and enjoyed it, and it was great!

DR. DIAMOND: Why couldn't it have been this way before?

JERRY: Yeah, why did I have to go through all this misery of thinking that I wasn't performing and that I had lost my capabilities.

DR. DIAMOND: Isn't that a problem with all of us—we become spectators, rather than participants. We ask, "What am I supposed to be doing?" rather than, "What can I do?" Shouldn't we concentrate on what we have, rather than on what we don't have?

BILL: This business about fear— it can be emotional fear, too. With fear that, once you are handicapped, you're not going to be able to live up to the expectations that you've been taught in the past other people have of you and you have of yourself. Being in a wheelchair, they don't have the same expectations; they kind of wonder if you can or you can't. Once you show that you can have intercourse you can also show them what would normally be progressing steps to intercourse. You can show them that you've had good experiences and pleasurable experiences, and the orgasm doesn't become important anymore—or the typical intercourse methods.

DR. DIAMOND: Did you have different experiences as you went through different ages? Many of you have had your handicaps for quite some time.

MICKIE: I've had a rather different type of life. I lost my first husband because of my illness. He couldn't face up to having a disabled wife and two small children. The second time around, it was great. However, before my husband died, he was, for the last two or three years, so very ill that for us there was no more sex as most people think of it. But there was still a deep affection between us. I built my life around different types of activities, so I can't say that I really felt too great a lack in my life because he was still very affectionate, very sweet to me, and showed me lots of love and attention, and I tried to do the same for him. That was important. The fact that we no longer had typical sexual relations just ceased to be of any importance to either one of us.

DR. DIAMOND: Do any of you get the feeling that either the spouses or lovers, or what have you, are hesitant in initiating sex because of the handicap? How do you overcome that?

GEORGE: I feel that one of the greatest difficulties with my whole family is lack of being able to say it's all right. We begin to have a profound doubt of our own feedback mechanism. You know what I mean—an acceptance. That I'm okay where I'm at is kind of cut off because of this regression. You know, when you're on your own, you lose that trust in yourself.

DR. DIAMOND: Is there anybody that you can communicate with? Your physician or your spouse?

GEORGE: Somewhat; I think more would be helpful.

DR. DIAMOND: Francis, whom do you talk to when you have problems?

FRANCIS: I sometimes talk to my parents, counselors, or probably with the girl I'm dating. I find that the girls are understanding. I talk about the problems that I have and they feel compassion about my problems and I feel that they understand.

DR. DIAMOND: What is your biggest problem that you think you've had and overcome? Jerry, how about that?

JERRY: I really believe that the biggest problem was living up to an expectation that wasn't expected at all.

DR. DIAMOND: But now you don't worry about it at all?

JERRY: No, I don't worry about it. That's just the way it is. My wife is a wonderful woman. She's very loving and we've established a new relationship on a different level.

DR. DIAMOND: You just don't have the movements.

JERRY: Right.

DR. DIAMOND: Bill, how about yourself?

BILL: I agree with that. That the most important thing is to get your own self-confidence and just do what comes naturally when you're with your girl.

DR. DIAMOND: How do you do that?

MICKIE: Well, you throw your inhibitions out the window and let it all hang loose.

DR. DIAMOND: How do you do that though? How do you throw out your inhibitions if you've got them?

BILL: It's just a matter of confidence. The first time you may not take advantage of what you later perceive to be the girl's willingness, then you verbally kick yourself in the rear end. The next time, by God, you're not going to make the same mistake twice! You're going to go ahead and do it.

DR. DIAMOND: Mickie, you said something I think is crucial about getting rid of your inhibitions. How about those feelings with guilt? That you may be doing something that somebody else says is not normal?

MICKIE: That is a very hard thing to overcome, but you've got to make up your mind; either you're going to take happiness now while it's there waiting for you or forget it because you're not going to come back and do it again. You know—it's that simple. It isn't like having a piece of cheese in the "refrig" and a week later going and getting it out. There's no way that you're going to be able to do that. So you've just got to say—maybe we'll try something else.

DR. DIAMOND: Sex, in terms of genitals, is important but, in terms of personal worth, getting along with somebody and self-worth are perhaps more important.

MICKIE: Oh, I think so!

WHAT does the discussion illustrate? The dialogue demonstrates how the separation of expectations and capabilities is narrowed when guilt feelings are lessened. It goes further, as we must, in reducing guilt and lessening the gap between expectations and capabilities by legitimately doing away with false expectations. For example, we do away with the "myth," which, in essence, states that the only satisfactory means of expressing oneself sexually and achieving satisfaction is with an erect penis in a well-lubricated vagina. For the able-bodied as well as the handicapped, sexual satisfaction is possible without these practices and, in fact, may even be more satisfying. Hands, mouth, feet, any body part may be used any way to achieve satisfaction, and one means is not, a priori, to be preferred over another. Presenting this concept in a positive way can be very helpful to clients.

Further, we should do away with the "marriage manual" formula and concept, which views some activities as foreplay, some as afterplay, and only coitus as "the real play," each "play" with a prescribed time allotment and sequence. We must advocate that anything goes, for however long or in whatever sequence. This is as true for those whose motor functions are compromised as for those with a sensory loss. Persons should be encouraged to maximize the use of those functions that remain, rather than bemoan the nonuse of those functions that are lost.

We can do even more to lessen the gap between capabilities and expectations by suggesting the use in sexual expression of some of the same types of devices we would offer to lessen the gap in job performance between capabilities and expectations. I'm referring to the use of prostheses. We certainly encourage the use of and recommend artificial arms, legs, or eyes where they will serve a function, even a cosmetic one. We can do similarly in a sexual situation. While the use of false breasts has become common for women with mastectomies, we might encourage or at least recommend the use of dildos, vibrators, or anything that the client might find usable, functional, or cosmetic, in his or her sexual relationships.

While this might strike some as inappropriate, I think we have to realize that the same reasons other prosthetics are used in normal, everyday life apply to their sexual use. This actually should be seen as quite appropriate for the handicapped since many able-bodied use them routinely; in fact, the able-bodied provide the major market for their present use. The aged and arthritic and hand amputees can certainly use vibrators where they have lost hand function, and an artificial penis or vagina also has its use, for either solitary or mutual pleasure. While it may take some education on the part of both the client and the partner to accept these devices, with professional encouragement they can accept or reject them without the connotations of guilt that might otherwise go along with their use or consideration. It is to be emphasized that these devices are presently available and are most often used by the able-bodied, so they should not carry a special stigma for the handicapped. These should legitimately be sold in surgical supply stores as freely as in the porno supply shops, where they are presently sold.

Prostheses help those with motor problems. For those with a sensory loss, I will offer a suggestion that is also helpful for those with reduced motor abilities, i.e., maximize the use of all possible senses. If a person is deaf or blind, then obviously maximal use is made of other input means. A soft touch or caress or kiss on a sensitive area may be quite stimulating, and we can increase or multiply the use of available senses by reading or viewing explicit, sexually oriented material or pornography, by the use of perfume, good food, fancy candles, music, and the like. Certainly it should be reiterated here that talking and touching, the most basic means of communicating, must be increased. Eye contact and language are to be encouraged. Novelty and spontaneity also have erotic overtones that should be exploited for maximum sexual satisfaction.

The dialogue also stressed another major point made earlier. That is, satisfaction is quite different from orgasm. Further, sex is, itself, usually used as a means of communicating deep feelings. These feelings can be provided with simple touches, glances, and personal interchanges, which don't require elaborate gymnastics or idealized anatomy. Satisfaction is most often a result of good sexual communication and shared intimacy and is independent of orgasm. Satisfaction and orgasm may be simultaneously sought after but separately achieved. If we make this idea acceptable to our clients, I think we will have helped them in a major way.

IN conclusion, I would like to apologize for not discussing, in detail, special problems associated with pregnancy or contraception, or dealing with the special issues and concerns of the mentally retarded. These must await a subsequent publication. What I did hope to do, however, is alert your attention to: *1)* the difference between public and private sexuality; *2)* the separate concerns attendant to genital satisfaction, love, reproduction, and marriage; *3)* these aspects as different, dependent upon the client's life stage; and *4)* sexuality as viewed from various perspectives. Further, I tried to show how to deal conceptually with several overriding issues for the handicapped, i.e., expectations and performance, guilt, and communication. Lastly, I tried to provide some specific ideas to help meet these issues.

I would reiterate that everyone's sexual life can be improved by *1)* increased communication; *2)* decreased guilt with anything mutually satisfying; and *3)* education and ease in dealing openly with sexual issues, so that expectations are more realistically in line with performance capabilities. All of this serves the human need for satisfaction in self-assessment and interpersonal relationships. This satisfaction is seen as the first stage in a person's successful road to rehabilitation specifically, but contentment with life's lot generally.

What I am offering for you to master are concepts that don't take a large budget or special, elaborate training. What it does take is empathy, and those in rehabilitation, by virtue of the career choice, have usually demonstrated an ample supply of this.

Toward An Understanding Of the Rehabilitation Of the Disabled Adolescent

RICHARD T. GOLDBERG, Ed.D.

Summary

During late adolescence, emerging individuality and sexual identity allow teens to make post-secondary school educational, vocational, and romantic plans. A strong ego identity also leads to socialization. Because teens with chronic mental or physical disabilities experience delayed identity development, vocational rehabilitation should be based on emotional and mental growth rather than chronological age.

Typical adolescent problems of separation, independence, body image, sexual identity, aggression, and depression are exacerbated in persons with disabilities. Resolving these problems prior to vocational placement requires youth-focused social skill development, individual or group sex counseling, and vocational training tasks that parallel the developmental tasks of adolescents. Additionally, long-term post-adolescent counseling and adjustment services assured through federal legislation will help integrate adolescents into their communities.

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Introduction: The Tasks of Adolescence

ADOLESCENCE presents a series of developmental tasks that are mastered with difficulty by the able-bodied youth. The challenge of breaking away from dependence on family and the counter pull of maintaining ties with home may disrupt the hitherto tranquil path from child to adult status. Adolescent turmoil is normal. When a young person in late adolescence (age 17-20) shows no signs of rebelling against parental authority, then we may suspect in American culture delay in normal development.[1] Persistent clinging to family, loss of affect in peers, and schizoid withdrawal from interests outside the home should be cause for referral to a mental health provider. Too often families ignore the incipient symptoms of emotional disorder in the compliant, passive, conformist youth whereas they may seek help for a rebellious, acting-out counterpart.

The tug-of-war between independence and dependence is complicated by the reemergence of basic instinctual drives of agression and sexuality. The delicate balance between the expression of drives and the formation of conscience is tipped by the primal urge of biology. Adolescents become preoccupied with the internal process of their own body. "Bad" thoughts concerning sexual exploration of the body, masturbation, desire and fear to explore the bodies of other persons, parents, siblings, of the same sex or of the opposite sex, may dominate a large portion of the adolescent's day-dreams and reveries. Coming to terms with one's own sexuality will lead to the formation of an adult personality.

The twin processes of individuation and sexual identity are necessary to the completion of other adolescent tasks. The making of an educational plan after secondary school presupposes that an adolescent can make an independent choice of future schooling with the help of a knowledgeable adult. The making of a realistic vocational plan leading to an adult career presupposes that an adolescent can accept individual responsibility for a career choice. Finding a suitable lover or mate or choosing to remain single (and, perhaps, celibate) presupposes that an adolescent has formed a stable sexual identity.

Other tasks confronted by the adolescent in American culture are the development of a comfortable body-image and feelings of positive self-esteem.[2] The worship of the beautiful body and the cult of physical attractiveness are reinforced by the media paid by the advertising industry. For the able-bodied adolescent it is often difficult to develop an adequate body image that can withstand the taunts of one's peers. Flat chest, thin legs, underdeveloped testes, minimal secondary sexual characteristics, and small stature may threaten the able-bodied youth's concept of one's self as a man or a woman.[3]

Finally, the successful formation of identity may lead to socialization. The adolescent may take a place in the adult world as a worker, lover, parent, or active community leader. Once the dangerous shoals of adolescence are passed, the individual may fuse an identity with others in the greater organic body of the community.[4] The inability to form a strong ego identity in adolescence leads to role confusion in the Eriksonian sense, and to regression.

Application to Rehabilitation

Although never easy for the able-bodied youth, the tasks of adolescence, when superimposed upon the burdens caused by chronic physical or mental disability, are laden particularly by conflict and strife. Any rehabilitation program established for the disabled adolescent must first attend to the resolution of normative developmental tasks. It is premature to provide vocational rehabilitation programs for adolescents who are functioning at the developmental level of pre-adolescence. Too frequently disabled youth who have reached employable age (16 or above) are referred to state rehabilitation agencies and then determined to be ineligible for service because of lack of previous social preparation.

In an attempt to learn more about the transition from child to adult status among disabled youth, several studies of adolescents with a variety of disabilities and with different levels of social competence, have been analyzed. Mindful of the developmental tasks of adolescence, the impact of chronic disability, hospitalization, and medical treatment upon their lives will be explored. What follows is an attempt to understand the special problems of disabled adolescents and to recommend rehabilitation programs to meet their needs.

Problems of Separation

For the able-bodied adolescent, the problems of separation from the family may be difficult to resolve. For the disabled adolescent, prolonged medical treatment and chronic hospitalization intensify the conflict of separation. Adolescents in a hospital setting are especially rebellious against the constraints of having to take doctors' orders, comply with medications, and abide by hospital rules. At a time in life when they want to become independent, they are required to be dependent for long periods. Hospitalization reinforces their dependency needs as the adolescent must depend on the doctor, nurse, or therapist to carry out daily tasks. The adolescent may express anger toward the hospital staff as a way of coping with separation. If they are angry, they can justify rebellion. If they are angry toward the parents, they can separate from them more easily.

The problems of separation are even greater when the adolescent has a mental illness. Anxiety over separation may provoke a sudden flight into independence. Sometimes this flight from family succeeds and the adolescent works through the developmental crisis. In many cases, however, the individuals may have to experience a transient schizophrenic episode over and over again until strong enough to stand on their own. This may explain, in part, why brief psychotic episodes may be rolled up in the adolescent turmoil state.[5]

Problems of Body Image

Every adolescent must come to terms with body image. The cultural ideal of physical wholeness and physical attractiveness sets a standard, which visibly physically disabled persons find difficult to meet. Disabilities with visible disfigurement have more social stigma attached to them. In a comparative study of the adjustment of children with congenital heart disease and facial disfigurement, we found that an invisible congenital defect with severe physical limitations had a less deleterious effect upon social and vocational adjustment than a visible disfiguring handicap with slight physical limitations.[6] Cystic fibrosis presents another disability with slight social handicap due to minimal visible disfigurement.[7]

For adolescents with obvious physical handicaps, such as paraplegia, spinal bifida, and muscular dystrophy, the problem of incorporating a distorted body image into their self-concept becomes crucial. A wheelchair, a brace, a crutch becomes part of the adolescent's body image. Too frequently physicians and other helping persons emphasize the negative aspects of the disability by concentrating on what the adolescent *cannot* do. Children who have been placed in casts for orthopedic handicaps develop a negative body image as they compare themselves with their able-bodied peers. Dembo, Leviton, and Wright, in a study of persons with amputation, suggested the necessity for a change in values so that the personal assets of the disabled individual may be substituted for a comparative value based upon physical appearance.[8]

Problems of Achieving Independence

The disabled adolescent has the special problem of achieving emotional and financial independence despite marked dependence upon parents, friends, and health professionals for the treatment and care of the disability. Society has encouraged the disabled child to remain dependent in sheltered situations at home and school.[9] The pattern of learned helplessness may hinder the disabled adolescent from taking those steps required to prepare for independent living in the community.

Repeated hospitalization for chronic illness reinforces dependency. Adolescents with cystic fibrosis, congenital heart disease, and muscular dystrophy may spend many months in treatment. Their growing sense of isolation, their feelings of helplessness that they will never get out, their anger at parents for placing them in treatment—all these factors tend to diminish their independence.

Adolescents who have been hospitalized since early childhood may learn to become overly compliant. In a study of institutionalized patients at the Massachusetts Hospital School in Canton[10] it was found that adolescents in the age group 14 to 17 tested two years below their able-bodied counterparts in acceptance of responsibility for making educational decisions. When institutionalized adolescents are required to leave school, they may become frightened, anxious, and withdrawn. After many years of enforced dependency, they are ill prepared to meet the tasks of career building or future training.

The hiatus between special school and the vocational rehabilitation agency is marked by career indecision. Until the recent passage of P.L. 94-182, few states provided guidance services for the group of adolescents who had finished high school and who were considered "not ready" for rehabilitation services. Yet it is just this group that needs intensive guidance.

Problems of Sexual Identity

Every adolescent has the problem of attaining a stable sexual identity. Erikson points out that the danger of the stage between childhood and adulthood is role confusion. "Where this is based on a strong previous doubt as to one's sexual identity, delinquent and outright psychotic episodes are not uncommon."[4] Able-bodied adolescents learn to explore their sexual parts through the normal course of sexual play. As adolescents begin to show an interest in the sexual parts of their friends, there are normal opportunities for sexual exploration at school dances, at private homes, at the beach, and at athletic events. The formation of sexual identity also involves much time for conversation with the opposite sex (or same sex), since one's ego ideal is reflected in the eyes of another.[4] The wedding of human sexuality with the deeper, more mature expression of love may come in late adolescence or young adulthood.[11]

The disabled adolescent has special problems in resolving the developmental task of sexual identity. Some of the problems are attributable to cultural restraints, taboos, and myths. Some problems are specific to the disability. Still others are caused by social isolation, institutionalization, and chronic, intermittent hospitalization.

Parental attitudes toward their disabled children have been repressive and controlling.[12] Many parents consider their disabled children to be asexual and to have no chance to marry, reproduce, and lead a normal sexual life. They especially consider children disabled from birth to be incapable of ever developing sexual relationships. The disabled child may learn from the reaction of the parents that his or her body is ugly and sexually unattractive. In high school, the disabled adolescent may be excused from classes on sex education because the school principal considers sex education irrelevant for the disabled person.

Attitudes of medical personnel have been no less negative. One physician told his adolescent patient with spinal bifida that she should never contemplate having normal sexual relations because she could have no vaginal sensations.[13] Although spina bifida does impair the urogenital system, sexual function may be present and limited genital sensation may be aroused.[14] In adolescent boys with spina bifida, 75 percent are able to obtain erections. In a series on 26 males and 26 females with spina bifida, ages 12 to 30, 80 percent of males and 90 percent of females had poor self-images. The uncertainty about sexual function contributed greatly toward their poor self-image.

The achievement of sexual identity is especially difficult for adolescents with intellectual disabilities. For many years it was felt that mentally retarded persons should be restrained from sexual activity lest they procreate a child whom they cannot raise. Sex education for the mentally retarded is a recent innovation fraught with fear by parents and community.[15] In a recent study of 430 mentally retarded persons exposed to a sex education program, it was found that many students showed positive changes toward their sexual feelings and were more open about communicating their feelings. In another study of adolescents with learning disabilities, consisting of a heterogeneous group of young men and women (ages 16 to 22) with cognitive and behavioral problems, students' responses to sex education workshops varied from acceptance to anxiety.[16]

Adolescents with sensory disability have particular difficulty in learning sexual roles and functions. Blind persons have to be taught to explore sexual parts by touching. Hearing impaired individuals may feel comfortable in discussing sexual issues with their peers. Deaf adolescents in high school may feel isolated from their able-bodied peers because of communication problems. Group counseling may provide a comfortable setting for discussion of sexuality among deaf adolescents.[17] Deaf-blind adolescents have great difficulty in interpreting sensations from their body. Deaf-blind children must be helped to become acquainted with their body and with the bodies of siblings and parents.[18]

Problems of Aggression

During the adolescent years the aggressive drive is reinforced by changes in the endocrine system and accelerated physical development.[5] Moreover, the capacity to implement the aggressive drive is greatly increased during adolescence. Severe acting out behavior, alcoholic binges, delinquent offenses, promiscuity, and drug related offenses are more prominent in adolescence. Frequently, the adolescent acts out aggression in an antisocial way in order to assert independence of parental and community authority. Antisocial acts may eventually bring the adolescent into conflict with the court. At that point rehabilitation programs may be offered the adolescent to help resolve problems in a socially acceptable way and adjust the person's aggression to the needs of society.

The full blown syndrome of antisocial personality may develop in the adolescent years. The antisocial personality, according to Hudgens,[19] begins in childhood, persists in adolescence, and tends to be resistant to treatment. The disorder is chronic when it includes at least four symptoms, including school problems, poor work history, excessive drug use, excessive alcohol use, three or more nontraffic arrests, habitual physical aggression, sexual promiscuity or perversion, suicide attempts, habitually impulsive behavior, and lack of guilt. The adolescent with an antisocial personality is the most likely individual to come to the attention of school authorities, the police, the courts, and the community. This type of psychiatric disorder may get treated in the correctional system or in the mental health system, depending on whether the behavioral offense leads the individual to confrontation with the law. Even when the adolescent is treated vigorously, this disorder may develop into a lifelong pattern of criminal and antisocial acts.

Problems of Depression

The most serious problem of psychiatric illness in the adolescent years is attempted suicide. This is more common in girls than in boys, and is more often attempted than completed. Although adolescents are less likely to complete suicide than are depressed adults the figures are large enough to warrant immediate attention. Suicide is the fifth leading cause of death among adolescents.[19] Suicide prevention centers, "hot lines," and emergency rooms of general hospitals are flooded with calls from emotionally disturbed adolescents. There are few centers that specialize in counseling the physically disabled youth who is threatening suicide, yet this group is enlarging as more children with chronic severe handicaps survive life-threatening illness and trauma.

Problems of Educational and Vocational Development

The educational and vocational development of adolescents is linked inextricably with the formation of sexual identity. The reason why many rehabilitation programs for the disabled adolescent fail is that they concentrate exclusively on the specific problems of vocational training and finding a job. Vocational rehabilitation should be considered the end product of many internal and external forces impinging on the adolescent's life. The aforementioned problems of separation, independence, body-image, sexual identity, aggression, and depression must be resolved before a vocational choice can be made. Amid all the turmoil of adolescence, the able-bodied/disabled youth cannot be expected to make a realistic choice without a great amount of help.

Able-bodied adolescents attempt to resolve the problems of vocational development by making choices that are consistent with their concept of who they are. Vocational choice defines a person's career goals; it is a summing up of abilities, interests, and values on one side, and the opportunities of the labor market on the other side. When the choice is made realistically, it represents a compromise between aspiration and reality.[20, 21]

But the disabled adolescent may lack the experiences at play, school, and part-time work that are helpful in making vocational choices. The disabled adolescent may have unrealistic fantasies or goals, may deny physical or mental limitations, or may overestimate the effect of these limitations upon a vocational choice.

In a recent study of five groups of handicapped children compared with a group of able-bodied children in grades 6 to 12, it was found that handicapped children tested significantly lower than normal children on all measures of vocational development.[10] The rank order of handicapped adolescents by group were: cystic fibrosis, congenital heart, orthopedically handicapped, facial burns, and juvenile delinquency. Only the group with cystic fibrosis approached the high score of the able-bodied group. Children with cystic fibrosis and congenital heart disease were hospitalized at a private hospital and came from a higher social class. Children with facial burns and delinquency came from the lower socioeconomic class. All children had a lack of occupational information about curricula and jobs, and few had been exposed to vocational counseling while in the hospital, clinic, or school. By the time they were referred to a vocational rehabilitation agency, they were significantly lagging behind their normal age and grade peers in educational and vocational planning.

Our expectations for disabled adolescents are based on the premise that they can perform normally once their disability is circumvented and their abilities are harnessed through training. However, any training program is bound to fail unless the handicapped youth is ready to accept vocational guidance. Our research and clinical experience show that the handicapped youth must be helped to resolve the developmental problems of adolescence before entering vocational training programs.

Rehabilitation Programs for Disabled Adolescents

The aforementioned problems must be met by specific rehabilitation programs. Until recently rehabilitation programs have focused primarily on adults. In a comprehensive search of the literature, a few programs that deal exclusively with youth were located. The majority of these programs focus on educational and vocational problems.

School and Work Programs

Hunter and Zuger[22] discussed the establishment of a summer work program for severely physically disabled youth at the Institute of Rehabilitation Medicine, New York, in conjunction with the New York State Office of Vocational Rehabilitation. The objectives were to provide a summer work experience in the private sector, to enhance the vocational development of handicapped youth, and to introduce a group of handicapped youth to private employers who might later employ them. As a result of the program, 71 high school and college students were placed in a variety of jobs, ranging from file clerk to editorial assistant. A pilot study has been undertaken on nine students to determine the long-range outcome on their vocational development. The results thus far on work values, vocational maturity, job awareness, and change in goals have been equivocal. One problem is that statements about significant change cannot be made without an adequate control group. Nevertheless, this pilot program presents an interesting exploratory model that other agencies might replicate and test with a statistical control group.

The use of an alternative school for both able-bodied adolescents and adolescents with emotional disturbance has been advanced in recent years. The alternative school may provide a limited academic program, up to three hours a day, in a self-contained classroom. Class size is small and the teacher-student ratio is reduced. The alternative school emphasizes basic skills necessary to obtain work. The remainder of the day may be spent in apprenticeship in local industry and avocational interests. One study by Strathe and Hash showed that early adolescents developed greater self-esteem, as measured by the Coopersmith Self-Esteem Inventory, as a result of an alternative school experience, although older adolescents showed no change.[23]

At the Human Resources Center (Albertson, Long Island, New York) a special program provides career alternatives for physically disabled persons. Project PREP (Programmatic Research on Employment Preparation),[24] jointly funded by the Rehabilitation Services Administration and the Bureau of Education of the Handicapped, provides a program in which a high school student is brought through a process from career awareness—in which knowledge of the self, ability for independence skills, and career opportunities are explored—to placement in industry. The curriculum includes bringing in successful career models who relate their experiences and inform students about their careers; business ventures, where students participate in various phases of a business experience; field trips to work sites; a work experience program, where youth engage in paid work experience; and a transitional living experience, where youth have the chance to live without parental or custodial authority in a barrier-free residential setting. The most important element is the integration of the regular curriculum with work experience.

Social Programs

The concerns of adolescents extend beyond the development of educational and vocational skills. Yet few programs emphasizing the development of social skills are available to them. Abramson and others[25] propose three solutions to the problems that handicapped youth must face in everyday life. The first is modeling. As developed by Bandura, modeling requires a teacher or a set of films that demonstrates correct social behaviors to be learned by the handicapped adolescent. These behaviors might include school work and sexual encounters. Most human beings learn social behavior through imitation. Since handicapped youth often are denied access to the most fundamental social behaviors—for example, sex play—it is necessary to provide them with models. A second solution is role playing. The handicapped adolescent is encouraged to assume the role of worker, college student, or sexual partner with controlled conditions. Role playing can be facilitated in a group setting under a trained leader who knows how to reduce anxiety. A third solution is self-instruction, in which the adult model first performs the task while talking aloud; the youth then performs the same task under the direction of the model, and learns to perform the task while talking first aloud, then in whispers, and finally by private speech. Of the three proposed solutions, the authors consider the last to be the most promising.

At the New York University Medical Center, Institute of Rehabilitation Medicine, a new program has been developed to meet the special needs of mainstreamed physically disabled adolescents.[26] Although the public schools attempt to meet some of these needs, the public school program primarily meets academic needs. Therefore, the Institute of Rehabilitation Medicine has begun to develop and coordinate after-school programs in New York City that already exist, such as YMCA and YWCA boys' and girls' clubs, and to explore programs to provide sexual counseling, extensive prevocational planning, and social and interpersonal skills.

Sexual Counseling

Since problems of achieving sexual identity are prominent among disabled adolescents, programs of sexual education and counseling must be provided when they reach sexual maturity. Sexual counseling can be provided either in groups or in individual sessions. Mayers[12] described a program of sexual counseling following spinal cord injury and a variety of chronic physical disabilities. Group membership consisted of 10 disabled individuals, one able-bodied husband of a disabled woman, and a psychologist. Although members of this group ranged in age from 22 to 39 years, they focused on many problems that were encountered with their parents. Those who had been disabled from birth or early childhood recalled that their parents would not acknowledge their sexuality, would not discuss sex with them, and dissuaded them from having sexual relationships with other disabled children. In the group, disabled young adults were encouraged to deal with their sexuality in a manner that was denied them while adolescents.

Often sexual programs for able-bodied, as well as disabled, persons focus almost exclusively on the anatomy, physiology, and function of the sexual parts. What is needed is a program that permits the open expression of feelings. Too often disabled adolescents have bottled up their feelings about sex, just as they have repressed their feelings about their disability. Along with the sexual revolution of the 1960's and 1970's there has come the revolution of the rights of handicapped individuals to enjoy *their* sexuality. Expression of sexuality is perceived as recreation as well as procreation. As one author put it, "it is an activity people choose to engage in, during their leisure time, for enjoyment and personal satisfaction."[27] Sexual relationships are also a way of meeting people, developing adult interests, and fitting in socially.

Vocational Rehabilitation Programs

Until passage of the Rehabilitation Act of 1978, vocational rehabilitation programs for disabled adolescents under age 16 were minimal or nonexistent. Therefore, in reviewing the literature, criteria were broadened to include vocational training programs for students still in high school or college.

Cooper[28] described a small, structured occupational training program for severely handicapped persons in the public schools of Atlantic County, New Jersey. Two full-time vocational counselors worked with 38 students, evaluated their vocational potential, and placed 17 of them in private industry. Close contact with business leaders in the local community and with the New Jersey Rehabilitation Department was very instrumental in obtaining jobs. Results indicated that 25 students were placed once, 4 students were placed a second time, and 4 a third time. While in training, the New Jersey Rehabilitation Department supported 17 students. Although this project began before the passage of the Rehabilitation Amendments of 1978, the results showed that a public school can be coordinated with a local division of vocational rehabilitation and other private agencies for the purpose of job placement in the community. This project foreshadows a model for special education and rehabilitation.

Kohring and Tracht[29] reported the introduction of a work evaluation program for severely handicapped high school students in Chicago. The group consisted of students from two schools, one a special unit for deaf and hearing impaired individuals, populated mainly by black, male, ungraded students. Students were evaluated at a nearby Goodwill Industries training unit, and were given practice in taking tests, filling out application forms, and exploring vocational areas. The third phase of the program provided a "hands on" work experience in one of Goodwill's training areas. Periodic staff conferences were held at the school and joint planning took place between Goodwill and the school authorities. Results indicated that 12 of 18 students evaluated at Goodwill were able to enter a vocational training program at Chicago's Rehabilitation Institute. Four of 21 graduates who finished public school in June, 1976, are working and one is in college. The program illustrates how a community rehabilitation agency and a public school can jointly plan a vocational evaluation of a student with severe handicaps prior to completion of high school.

The vocational development of the disabled adolescent requires a rehabilitation program that provides a continuous series of vocational tasks analogous to the developmental tasks of adolescence. This means that vocational rehabilitation programs should provide experiences of separation, independence, and identity formation. Separation from parents can be encouraged by providing work experiences in supervised settings away from home. The able-bodied youth may find summer employment in an overnight camp or in after school work situations. Disabled youth should be provided with work opportunities in settings where parental protection is replaced by adult supervision. Camp counseling, sheltered workshops, and transitional living environments made possible by independent living centers would be helpful. Since problems of separation and independence must be resolved by late adolescence, rehabilitation programs must provide opportunities for transitional living in conjunction with work.

Until now Goldberg,[30] Super,[31] Tiedeman,[32] Hershenson[33] and others have been calling for a vocational developmental sequence that emphasizes a logical series of vocational phases. As applied to disability, Goldberg[10] has shown that disabled adolescents do not always go through successive phases of development, and that when they do, they tend to score an average of two years below their age and grade peers. For 30 years the field of vocational psychology has been focusing on questions of vocational choice, aspiration, interests, adjustment, and satisfaction. These questions, no doubt, are important. Nevertheless, important problems of adolescence have been left out. Adolescents cannot make choices without first resolving the problems of separation, independence, and sexual identity. What I suggest is that the field of vocational psychology break away from its moorings. Let us begin a new line of empirical research on the developmental problems of adolescence that must be resolved before vocational choice can take place. A new model of vocational development emphasizing independence and risk taking needs to be created. With the advent of independent living centers for persons with disabilities and the advent of alternative schools and lifestyles for able-bodied individuals, there has been created a possibility for studies of adolescence that are relevant to *their* real life problems.

Long-Term Adjustment

Few programs provide long-term counseling and adjustment services to adolescents after they leave high school. Yet long-term services are required by many disabled adolescents, especially those with mental illness, mental retardation, and severe physical disability. Adolescents with mental illness require the services of day hospitals, social clubs, and half-way houses to ease the transition between hospital and community. Adolescents with mental retardation require lifelong counseling and advocacy services to help them become integrated with the community. Studies of long-term adjustment of mentally retarded persons carried out at the Waisman Center[34] have shown that a large group of retarded students disappear from community contact after leaving school. This group frequently have greater difficulty in social adjustment since they lack rehabilitation services. Rehabilitation services offered to retarded students after high school are minimal at best. The real cost to the retarded young adults is that they do not get placed on jobs quickly or suitably for their limitations. Many of those eventually found by the Wisconsin studies are on SSI or general relief and live in community shelters in urban centers.

Rosenberg[35] found that 79 graduates of a public school for orthopedically handicapped persons attained a higher level of full-time employment and income when they were moderately handicapped and received vocational training after high school leading to a position protected by antidiscriminatory legislation. Of the 79 students, 64 percent entered college, 18 percent entered vocational training programs, and 18 percent sought employment. The relationship between college education and higher status employment held only for a few college graduates who had professional status. The normal relationship between college education and employment status did not hold for this population. The more severely handicapped individuals went to college, thereby postponing the time when they would have to seek employment.

Implications of Recent Legislation for Disabled Adolescents

The passage of the Rehabilitation Act of 1973 and the Rehabilitation Amendments of 1978 has ensured the provision of services to disabled children and adolescents. One important change is that rehabilitation services are no longer restricted to vocational rehabilitation. This change means that disabled adolescents in need of social skills and vocational development can receive comprehensive services for independent living as part of their rehabilitation program. These services may be given to any individual who is so limited by the severity of the disability that comprehensive services "are required to improve significantly either his ability to engage in employment or his ability to function independently in his family or community."[36] Comprehensive services may include counseling, housing, transportation, attendant care, recreational activities, job placement, physical rehabilitation, therapeutic treatment, prostheses, and health maintenance. These services may be used to meet the needs for independence and sexual identity that are so urgent in adolescence. At the same time, vocational needs are not ignored, as counseling and job placement are provided.

The new amendments make possible counseling throughout the life span of disabled individuals. Adolescents before age 16 may obtain prevocational services through an integrated program of special education and rehabilitation services. As disabled individuals proceed through secondary school to post graduate training, they may obtain vocational services. When individuals reach retirement age, they may obtain independent living services in order to remain independent, at home, and in control of their own life. Rehabilitation counseling programs should introduce training for life span counseling.[37] These programs should emphasize the coordination of special education, vocational rehabilitation, and welfare services for persons with permanent disabilities. Prevention of additional disability by timely medical and social services may be encouraged by the independent living amendments. Students in rehabilitation counseling should be placed as interns in educational settings and pediatric hospitals. As counselors, pediatricians, teachers, and school social workers get to work with each other, there will be smoother cooperation. An individualized educational plan needs to be integrated with an individualized rehabilitation plan. The transition from school to vocational training can be made a little easier when a multidisciplinary approach is taken.

The question remains whether the integration of special education and vocational rehabilitation will continue to be pushed by the Congress. At present there is hardly enough money to fund each program separately, and hardly enough money to provide independent living services for disabled adults. Although the Rehabilitation Amendments of 1978 call for independent living programs, the Congress has provided a pittance for this activity. When the political pressures of disabled adults are added to the political pressures coming from special educators, parents of disabled children, and disabled adolescents themselves, then it is clear that there are inadequate funds for equal shares of the federal "pie."

We, who are concerned with the rehabilitation of the disabled adolescent, need to advocate for special funding for this group. A section of the rehabilitation act should be earmarked for this group. Without special funding, money tends to get diffused throughout the system. One of the purposes of placing rehabilitation in the Department of Education was to integrate education for the handicapped with vocational rehabilitation. Let us make this possible by a strong amendment to the next Rehabilitation Act.

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Concepts of Adjustment to Disability: An Overview

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Summary

Individuals survive psychologically by adjusting to internally and externally imposed threats. Adjusting successfully to permanent disability involves integrating the reality of the disability within an individual's cognitive, affective, and behavioral functioning.

The major approaches to psychological adjustment focus on the individual's behavior and mental adaptability, society's influence on the individual, and a combination of both. The comprehensive view considers disability-adjustment an interaction between cognition and coping. Because it accepts, as a natural outcome, the multiple forms and levels of adjustment to physical and social situations, the integrative approach is viewed as productive.

ACCORDING to Lazarus,[44] the concept of adjustment may be traced to biology and Darwin's theory of evolution. Through the process of natural selection, species adjust to their environment in order to survive, and this is what constitutes evolution. Psychologists have come to apply this idea to psychological changes occurring within the person; psychological survival for the individual involves adjusting to meet threats imposed by internal and external demands.[44]

Loss and change of sufficient magnitude produce crises threatening one's psychological equilibrium. Marris[47] studied various situations involving loss and change, and he observed that people tend to be conservative (to attempt to preserve the status quo) and that changes producing considerable disruption cannot be acknowledged without distress. Caplan[8] has suggested that there are crisis situations that produce characteristic psychological responses to stress. Although these responses could be considered abnormal in the context of routine, daily life, they are deemed normal, because they are temporary and they are bound to the crisis situation. The distress that people feel at such times have come to be referred to as "transient situational disorders."[10] The concept of adjustment has come to be applied to this context; it explains how and to what end a person deals with crises that threaten psychological functioning.

Among the threatening situations to which the concept of adjustment has been applied, physical disability ranks high. Holmes and Rahe[34] studied stressful life events, and they found there are many sorts of changes in life, both positive and negative, which are stressful; physical illness or disability ranked sixth from the top of the list of those events seen as most stressful. A physical disability presents the person with a crisis calling for adjustment, primarily because of the major physical losses and changes it produces.[4,37]

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A physical disability produces changes in one's psychological and behavioral functioning. There are changes—in how one physically gets around, in thoughts and feelings, in ways of finding satisfactions, and in role functioning within the context of family, friends, and society at large. Adjustment to a permanent physical disability involves integrating the reality of the disability within the person's cognitive, affective, and behavioral functioning.

Defining Adjustment

Arriving at a satisfactory and generally accepted way of defining adjustment is often difficult. First, there are multiple definitions possible, all of which vary according to their theoretical perspectives; from one theoretical stance adjustment is defined in terms of relative levels of behavioral functioning, while from another it is defined in terms of mental attitudes. The review of the literature that follows will discuss in much more detail the various theoretical approaches and the ways in which they define adjustment to disability.

A second problem concerns terminology. There are many terms used by different writers to identify what appear to be the same or highly similar forms of psychological phenomena. For example, *adaptation* is a term often used synonymously with adjustment. *Coping* and *mastery* are terms also used to label psychological phenomena that are either a part of adjustment or almost the same thing as adjustment. Finally, the term *rehabilitation* is often used in ways similar to adjustment. It may be possible to clear up this lexical difficulty by putting together some sort of logical hierarchy or structure for these terms, but that is not the objective here. For the purposes of this discussion, only one term will be used: *adjustment*.

Lazarus[44] states that those who address the concept of adjustment have seen it either as a process through which the person goes in psychologically dealing with life's demands, or as a psychological outcome that the person achieves. It is not that adjustment should logically be divided in this way, but this is how it has been approached by others. These are not unrelated ways of viewing adjustment; just as the process of learning the alphabet culminates in the outcome of having learned the alphabet, so does the process of adjusting to a disability lead to the outcome of being adjusted to a disability. The single term *adjustment* is often used for both the process and the outcome, and this is the third complication arising when defining adjustment; adjustment may be defined either in an outcome-oriented way or a process-oriented way.

Good and Bad Adjustment

It is difficult to talk about adjustment without addressing the fact that a person's adjustment may be deemed good or bad. The matter of abnormal adjustment or maladjustment is implied in any discussion of adjustment. Many who address adjustment to disability include discussions of what they consider to be abnormal, maladaptive, and self-destructive responses that obstruct adjustment and rehabilitation.[11,20,33,35,51,62,72]

Values. Difficulties arise when it comes to asserting what optimal adjustment is or ought to be, because the criteria selected for distinguishing between good and bad adjustment will reflect personal values. It is thought that once value judgements enter the picture, adjustment becomes a culturally relative concept.[44] This becomes a problem, because we may wish to remain scientific and objective, and because there tends to be greater consensus about what is abnormal than what is normal.[70] For example, in a study of adjustment to physical disability, Bell[5] found much more inter-rater agreement on "bad" adjustment than on "good" adjustment.

It appears impossible to avoid values, and we may best deal with them by accepting their presence, by attempting to regulate their point of impact, and by being clear about them and their influence. It has been noted that, contrary to previously held views, science is inescapably imbued with paradigmatic biases[41] and is deeply informed by human values.[7]

Adjustment to Disability

Shontz[63] has traced the trends in theories of adjustment over the past 30 years. He notes that at first it was thought that the disability itself was the problem, rather than its psychological consequences, and it was expected that once the physical effects of the disability were reduced or counteracted, any psychological disturbances would subside. This rapidly proved to be an inadequate approach, because there were those who appeared unrehabilitated in spite of efforts to physically combat the handicapping consequences of the disability. Attention then moved from physical concerns to psychological concerns, and motivation came to be regarded as a major factor in rehabilitation; it was felt that lack of motivation led to failures in rehabilitation. Eventually, this too appeared to be an inadequate approach, because it was not an insufficiency of motivation but a blocking or misdirecting of it that obstructed rehabilitation efforts.[63]

Later approaches focused increasingly upon the psychological adjustment of the person in response to the disability. For the purpose of discussion here, these may be divided into three categories: *a)* approaches that are more oriented to the person, *b)* approaches that are more oriented to the socio-environmental context, and *c)* approaches that are integrative and view adjustment arising out of the interaction between the person and his or her social and physical environment.

Person-Oriented Approaches

Person-oriented approaches to adjustment to disability focus primarily upon what happens for the person in dealing with a disability. These approaches may be divided into those concerned with the behavioral aspects of adjustment and those concerned with the mental aspects of adjustment.

Behavioral Adjustment. Some explanations of adjustment to disability are drawn from behavior therapy. These are often the least complex explanations. Although many have contributed to the formulation of behavior theory, Pavlov's[54] principles of classical conditioning and Skinner's[66] principles of operant conditioning are basic to explanations of behavioral adjustment. Several researchers and theorists have applied this perspective in explaining rehabilitation and adjustment to disability.[17,22,23,24,26]

From the behavioral viewpoint, adjustment involves the person's actual behavior, not how he or she thinks or feels. Behavior theory is concerned with how stimuli and responses go together such that certain stimuli come to elicit certain responses and cause them to persist. The onset of a permanent physical disability radically alters the person's ability to respond with behaviors that previously were physically possible; as a result, the conditioned and unconditioned responses and the reinforcers or stimulus consequences experienced by the person prior to disablement are no longer operative after the onset of the disability.

The behavioral approach is simple and direct. Adjustment involves dealing with the person's changed capability to physically behave as much or in the same ways as before. This requires finding new behaviors and reinforcers. The process of adjustment involves the learning, over time, of new reinforcers and behaviors. Adjustment is achieved when the person establishes new rewards and satisfactions, and when he or she returns to premorbid levels of behaving.

Mental Adjustment. The focus here is upon the internal psychological life of the disabled person, and there is complexity and variety to these explanations of psychological adjustment. The discussion below will first examine the origins of this approach and two early applications. Then there will be a section dealing with the process of mental adjustment followed by one addressing the outcome of mental adjustment.

Theories of mental adjustment are primarily psychodynamic in nature. This orientation may be traced to the work of Sigmund Freud and his concepts of *a)* dynamic interaction between psychic forces or entities, and *b)* the process of psychological development taking place in stages. A major concern here is with how the person defends against and then comes to terms with objectionable internal and external events causing distress and psychic upset. The onset of a physical disability is a source of such psychologically objectionable material. In this regard, defensive reactions, such as denial and regression, are then seen as psychodynamic responses that occur during adjustment.[29]

The works of two psychodynamic theorists, Adler[2] and Schilder,[60] were sources for early explanations of adjustment to disability.[19] Adler was concerned with striving for superiority as a reaction against feelings of inferiority; his approach found application in the area of physical disability, because the experience of loss and devaluation produced by a disability was presumed to lead to feelings of inferiority. Schilder was concerned with body image and self-concept; changes in one's body caused by a disability were seen as having a direct bearing upon one's body image and self-concept.

Process of Mental Adjustment. The process of mental adjustment has most frequently been seen as taking place in stages. Although stages were initially used to explain the normal process of human development during childhood and adulthood, it came to have applications in other areas, such as crisis situations and transient situational disturbances. It has been used to explain the normal psychological responses to fatal illness,[40] and it has been used to describe the normal psychological responses to a permanent physical disability.[9,13,20,21,29,32,33,38,39,55,62]

There are some common characteristics to the various stages of adjustment presented by those concerned with physical disability; indeed, there are more similarities than differences. In order of appearance, the stages often discussed include the following: *a)* initial shock, *b)* retreat or denial, *c)* grief, mourning, or depression, *d)* reactions against dependency, which include separation anxiety, assertion, and aggression, and *e)* eventual adjustment based largely upon acceptance of the disability and renewed life involvements.

Although many see the process of adjustment occurring in stages, this approach has been criticized, and its value may be primarily heuristic. Those who espouse it offer little support beyond personal experience or clinical impressions.[69] Also, some research into various responses to disability have failed to find evidence to support this approach, or have found evidence contradicting it. For example, denial and depression may not be necessary or beneficial, and they may not occur in distinct stages.[16,43]

The major contribution of the stage-oriented approach to adjustment to disability may be the suggestion that this process involves moving from negative, rejecting responses to more positive and more accepting responses; at present this may be the best way to view the process of psychological adjustment to disability. There may be no distinct stages, and the sequence of psychological responses may not be the same for each person (they may occur in different orders, and some may be omitted), but the movement toward acceptance occurs nevertheless. This movement is manifested in terms of ongoing cognitive appraisal and reappraisal (recognizing and accepting the reality of the disability and changing values or attitudes about its meaning and consequences) and in terms of affective responses to it (feelings of helplessness, sorrow, despair, anger, and so on), which diminish over time.

Means and Akridge[48] have offered a concept of the process of mental adjustment that does not involve stages. Their approach contains a conception of what constitutes health, and this is manifested in what they call "healthy personing." For them, the healthy person appears to be an adequately adjusting person; that is, a person who, through a process that they outline, is continually acting constructively and maintaining open, facilitative relationships with others and the world around. For them, "the process of personal adjustment is the organization and disorganization of component processes such as the congruency of beliefs, values, and skills, or the integration of sensing, interpreting, feeling, intending and acting."[48, p. 26] This approach may be seen as similar to that taken by the phenomenological/existential or humanistic theorists; instead of looking at "adjustment," they examine "adjusting."

For Means and Akridge, the process of adjusting is circular, and it has inputs occurring where persons interact with their social environment. They describe the nature of the adjusting person in the following way. First, the adjusting person is one who utilizes basic communication abilities, which include "the ability to attend, recognize, and report feelings and intellectual interpretations of self, world, and others." Second, the adjusting person is able to locate, experience, and communicate a purpose that includes a "persistent conceptualization of self, others, the world, and time"[48, p. 26] and which has personal meaning. Third, the adjusting person possesses beliefs related to personal and social functioning; these include: *a)* belief in responsibility of each person for defining a purpose for being, *b)* belief in personal freedom and the responsibility for choosing, *c)* belief in the changing character of human existence, *d)* belief in one's self as a limitless resource to one's self, *e)* belief in the limited opportunities imposed upon life by mortality, *f)* belief in others as resources, *g)* belief that each person is part of a whole that is presently defined as mankind, and *h)* belief in the earth's limited ability to be a resource. Fourth, the adjusting person possesses values that actualize his or her beliefs, especially as they "yield specific decision-making power for choosing." Fifth, the adjusting person possesses achievement skills enabling him or her to "convert problem statements or personal deficits into goal statement, identify, schedule and rank behaviors which lead to the desired goals, constructively act, and monitor and modify."[48, p. 27] Sixth, the adjusting person possesses self-control skills in the areas of anxiety, concentration, and will power. And seventh, the adjusting person works toward an integration, which involves "continually converting one's belief system into behavior in more and more aspects one's life."

Outcome of Mental Adjustment. Seen as an outcome, mental adjustment involves the person's acceptance of the disability and self-concept. When adjustment is achieved, the person does not deny the fact and the difficulties it produces, and does not find his or her self-concept to be overly colored by the disability. Being adjusted to a disability means being able to obtain satisfactions within the limits imposed by the disability.[52] As a result, being disabled is different but not "bad."[9]

Acceptance has been seen as crucial to the outcome of psychological adjustment. Wright[73] believes that the person who has come to accept a disability is well on the way to being adjusted to it. Vash[71] similarly considers acceptance to be a fundamental aspect of dealing with a disability. Heijn[31] notes that a major task of adjustment is recognizing the fact of the disability and the event or circumstance that caused it. Grayson[28] sees denial and acceptance as mutally exclusive opposities, and from his viewpoint denial must be overcome for the person to accept his or her disability. Kerr and Thompson[39] go further and speak of acceptance as not simply the opposite of denial, but as the very substance of adjustment that must be achieved bit by bit over time. Dembo, Leviton, and Wright[15] insist that acceptance is more than simply becoming reconciled to one's fate; rather, it is a matter of arriving at a value change in which the disability is still seen as inconveniencing but not discrediting or overwhelming. Wright[73] describes what she feels are the four key aspects of acceptance of a disability: *a)* enlarging the scope of values, *b)* containing the disability effects, (*c*) subordinating physique, and (*d*) transforming values based upon comparisons between one's self and others into values based upon one's own assets and liabilities.

Acceptance of a disability has come to be viewed as related to one's overall self-concept. Research comparing responses on a self-concept scale to responses on an acceptance of disability scale indicates that acceptance is related to self-concept in general and that it is important to relate the value shifts occurring in acceptance with the broader perception of self.[46] Speaking from personal experience, Vash similarly relates acceptance to the larger issue of self when she states that "acceptance of disability was simply acceptance of myself; and there were parts of me that were harder to accept than my disability by far."[71, p. 153]

Socio-Environmental Approaches

The socio-environmental approaches look primarily at the influence of external situations on the person with a disability. Theoretical explanations and research findings are expressed in terms of the social and physical situations confronting the person.

Social Construction of Reality. The idea that reality is socially constructed offers a basis for socio-environmental explanations for adjustment to disability. Attitudes, roles, social networks, labels, and so on are all part of human interaction, and they form the basis for day-to-day realities of life. Similarly, social interactions result in the physical objectifications of social realities.

It should be noted that this is not a discussion of ultimate or absolute reality. What is of concern here is the medium of social interaction whereby reality is constructed, perceived, communicated, and maintained.

Berger and Luckman[6] point out that reality is sustained both within and by human perceptions and interactions. They suggest that, on one hand, people construct reality in the way in which they socially learn to perceive and communicate about the world around them, and that, on the other hand, they construct it behaviorally by ongoing social interactions (for example, through roles) and the manufacture of human artifacts (such as cities).

What is especially important about the social construction of reality is its dual impact upon the person with a disability. First, it is within the framework of existing social reality that the person comes to deal with his or her disability. Second, the fact that a physical limitation is disabling is partially a result of socially constructed realities, whether in the form of attitudes toward disability or architectural barriers. In the end, a person may be more disabled by social problems than medical conditions.[61]

Attitudes. Researchers concerned with sociopsychological aspects of physical disability have devised and employed scales to investigate the various forms and functions of attitudes held toward physical disabilities and persons who have them.[64,65,74,75] Those who have reviewed research into attitudes toward disability and those with disabilities[42,57,67] have noted that, either from the perspective of research or historical analysis, an impairment can evoke both negative and positive social responses. A person may experience difficulty in dealing with the stigma attached to a disability,[25] but at the same time a person may derive benefits from being in a marginal social status.[56] Wright[73] has discussed the ways in which a disability may result in both "inferior" status and a "salutary" status. Straus[67] has noted that, historically, those who have physical disabilities stand in the ambivalent positions of being deified or degraded. Conflicting expectations face the person with a physical disability.

Attitudes toward disability have a significant impact upon that part of adjustment involving acceptance. Within society at large, few people, if any, feel that "crippled is beautiful."[42] As a result, there is a limit to how far a person can go in embracing or accepting disability; one is not supposed to accept it to the point of liking it. Acceptance then becomes a matter of "biting the bullet and smiling at the same time—and about equally easy."[71, p. 151] The reason that crippled is not beautiful is that healthy is beautiful, and no one feels it is good or better to be disabled.[49]

Labeling. To an extent, labeling creates and manages deviant status. Labeling theory offers a perspective on disability that reveals how social phenomena are created and sustained through language. From this point of view, disability is seen as deriving from an interaction in which it becomes experientially real through labeling either by one's self or by another person. A physical impairment is thus seen as a disability (and all that implies for social interactions) when it is so labeled. Just as we might say that beauty is in the eye of the beholder, so might we say that disability is in the labeling of it. Among those who have applied this approach to disability are Jones,[36] who found labeling to be fundamental in the social management of black children with mental retardation, and Scheff[58,59] who found labeling to be central in identifying and managing disabled people who are receiving rehabilitation services.

Adjustment. Within the context of socio-environmental approaches to disability, adjustment may be viewed in terms of the individual, or in terms of society at large. In both cases, adjustment may be seen as occurring in terms of the physical situation or in terms of the social situation. In all cases, those writing in this area make little distinction between the process and outcome of adjustment.

1. *Physical situation in terms of the individual.*

It is the disability itself that constitutes the physical situation in terms of the individual person. The level or degree of impairment determines what sorts of physical adjustments should be made. The earliest approaches to adjustment focused upon physically compensating for the disability. These were attempts to change the person's environment at a very personal level. Thus, for example, poor vision may be compensated for by use of eyeglasses; similarly, adjustment to paralysis in the legs may involve the use of braces and crutches.

2. *Physical situation in terms of society at large.*

Recent attention has moved to the societal level. There has been a shift from the immediate functioning of the person's body to the physical situation determined by the overall environment. Inasmuch as the physical environment we all share is to some degree a product of human interaction, this concern with the physical environment facing persons with disabilities is actually a concern with the social construction of the physical realities, which in part make a disability disabling. If the physical environment, particularly that which is man-made, presents barriers or obstacles, the impact of the disability is magnified. The issue is one of accessibility; architectural barriers obstruct the free movement and exacerbate the limitations imposed by the disability.[30] Such barriers are the product of socially constructed reality, and at the physical level, socio-environmental adjustment involves the removal of as many architectural barriers as possible.

3. *Social situation in terms of the individual.*

At the individual level, the person adjusts within the context of roles. The person with a disability occupies a deviant position in society, and his or her social career is managed through roles. In this way, the person may have deviant status but still have roles that normalize functioning. Among the roles identified by Parsons[53] is the *sick role,* which involves exemption from normal social role demands under the condition that the sick person wants to get well and seeks medical treatment. Gordon's[27] research indicates that there is also an *impaired role,* which involves those who are chronically ill or disabled and which functions to maintain normal activities and social involvements. The issue the person faces is being different (which arises from being physically impaired), not being sick.[1] During the early stages of disablement, particularly if the person is acutely ill at that time, the sick role is most relevant; later, the impaired role becomes operative.

In addition to routine role functioning, the person must employ particular strategies for adjusting within the social context. Goffman[25] describes methods for *passing* or *covering* that are used to manage the stigma attached to a disability. Davis[12,14] notes that deviance disavowal is a major means for normalization. As Albrecht puts it:

> The disabled person redefines deviancy and values in terms of his resources, his own and others' expectations, and his reference group. What was "normal" for him yesterday is impossible or inappropriate for him today.[3, p 19]

It is not simply a matter of fitting into society, however. It is also a matter of utilizing social resources in adjusting, and friends or family may contribute a great deal in this area.

4. *Social situation in terms of society at large.*

Although it may seem somewhat strange to think of adjustment as occurring at the group level, this is a reasonable locus for adjustment. In this framework, it is not the individual who adjusts to disability but society as a whole which adjusts. Adjustment at the societal level would be in the area of commonly held attitudes toward disability. Toward this end, English[18] suggests the use of a program he has designed to alleviate and combat stigma toward those with disabilities on the part of the general public and those who are directly involved in assisting these individuals.

Integrative Approach

Of all the perspectives on adjustment to permanent physical disability, the integrative approach appears to be the most comprehensive; it includes both personal factors and socio-environmental factors. Adjustment is seen as occurring through the interaction between the person and the environment. Personal and socio-environmental factors are integrated in this approach. The ways in which the person adjusts, the amount of adjustment required initially, and the type of adjustment achieved must be viewed in the context of the person's background and the situation.

Lewin's[45] work has been seminal in this area. Furthermore, his theoretical stance has influenced several who have been concerned with adjustment to disability.[4,9,49] Lewin developed a field theory that integrates the person with his or her life space. The key principle in Lewin's theory is that behavior is a function of the interaction between the person and his or her environment.

A major feature of the integrative perspective is its attempt to view adjustment in relativistic terms. It has been noted that while we may wish to use a single scale for assessing adjustment to a disability, it should be a sliding scale, one taking into account variations between people.[68] Instead of limiting adjustment to some concrete state, process, or level of response, the integrative view takes into account the situation for the person and personality factors bearing upon how that person adjusts.

Moos and Tsu[50] have been among the most recent to elaborate a model of adjustment taking into account the integration of individuals with their environment. Although they intended it for use with respect to chronic illness, no disservice is performed by shifting it to physical disability. They see adjustment as taking place in the context of various background and personal factors, disability-related factors, and physical and social-environmental factors. Adjustment is based upon an interaction between cognitive appraisal of the situation produced by the disability, adaptive tasks required by the disability, and the coping skills the person possesses. The sorts of background and personal characteristics that are relevant are "age, intelligence, cognitive and emotional development, philosophical or religious beliefs, and previous coping experience."[50, p. 15] The illness-related factors include the nature of the disability or illness and the consequences of it (for example, whether it is painful or disfiguring and whether the portions of the body affected is vested with particular physical or psychological importance). The nature of the physical setting (including possible barriers to mobility, novelty of settings, and aesthetic qualities) and the social context (including family, friends, and health professionals) comprise the factors determined by the physical and social environment. All of these interact with each other, and in combination they influence the ways in which the person perceives the meaning of disability, the sorts of adaptive tasks that arise, and the coping skills that are employed. Moos and Tsu identify seven adaptive tasks, which may be divided into two categories. The first are illness-related, and they include: dealing with the pain and incapacitation, dealing with the hospital environment and special treatment procedures, and developing adequate relationships with professional staff. The second is a general category, and it includes: preserving a reasonable emotional balance, preserving a satisfactory self-image, preserving relationships with family and friends, and preparing for an uncertain future. There are also seven major types of coping skills, including the following: denying or minimizing the seriousness of a crisis, seeking relevant information, requesting reassurance and emotional support, learning specific illness-related procedures, setting concrete limited goals, rehearsing alternative outcomes, and finding a general purpose or pattern of meaning.

Summary and Conclusions

The intent here has been to review the various ways in which adjustment to permanent disability has been addressed. Some have viewed this topic primarily in terms of the individual; others have looked mostly at the person's social or physical situation; and finally, there have been those who see adjustment as involving both the person and his or her milieu. Although few would deny the need to take into account the overall situation for the person, it has been suggested here that those approaches that explicitly deal with the person's integration with their environment may be the most productive; in this way, our understanding of what it means to adjust to a disability will recognize multiple forms and levels of adjustment, which vary according to the person's psychological make-up and his or her social and physical situation.

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REHABILITATION

principles

The Habilitation Role of the Special Educator

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Summary

Special educators are incorrectly perceived as ordinary teachers possessing a few special skills for making traditional subject matter accessible. They are, in fact, rehabilitation workers assisting children who have little or no experience as disability-free individuals. As a result, special educators function as diagnosticians uncovering a child's developmental gaps and establishing programs, such as remedial reading, that provide the missed experience. The special educator acts as social facilitator, vocational trainer, and vocational guidance counselor.

For many children, habilitation is an original learning process creating continuous confrontation with themselves and their social status. Each developmental crisis requires guidance, reassurance, and instruction from teachers as well as referrals to other counselors. Because of their pivotal influence on the direction, quality, and efficacy of habilitation care, special educators deserve equal status and cooperation from their rehabilitation co-workers.

Special education is one of the less familiar disciplines associated with the rehabilitation team. In fact, more often than not, the special educator is accorded a second-class status in interdisciplinary relationships. The reasons for this are many. As a group, special educators are not altogether prepared for their teamwork role, their contributions tend to be minimized by other disciplines, and, because of their day-long assignments with disabled children, special educators rarely have the time for even the minimum level of participation and communication demanded by interdisciplinary cooperation. Insofar as the role of the special educator is constricted by the lack of understanding on the part of other professions, it can be corrected. The major objective of this paper is to contribute to this understanding by discussing the unique habilitation role and contribution of the special educator.

Special education is concerned with children and youth who, owing to intellectual, physical, and emotional limitations, would suffer educational deprivation if exposed exclusively to current general educational practices. The caseload of the special educator consists of individuals who require one or more adjustments in their educational programs, without which the growth process would be hindered. These adjustments vary in scope and intensity. At their least, they include remedial work within the framework of the regular public school class. At their most, they provide for the removal of the child into an entirely new environment that can be tailored to meet his individual needs. The settings of special education range from the regular public school class through special classes in the public schools to special day schools and residential institutions.

Educational service to disabled children differs from rehabilitation service to most disabled adults in one major respect. The latter has restorative connotations. Special education is developmental. Much of rehabilitation focuses upon assisting the individual to make optimum use of residual capacities, always keeping in mind that, in most cases, the person

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was once intact and lived as a nondisabled person. On the other hand, most disabled children and youths have no past as nondisabled persons. They will continue to grow as impaired organisms. Whitehouse[1] and others have differentiated these two groups, calling the latter the "habilitation" population. This characteristic of disabled children and young people creates major differences in emphasis and approach and forms the base point for the habilitation role of the special educator.

Special Functions of the Special Educator

Many rehabilitation workers are inclined to view the special educator as undistinguishable from other teachers except that he works with disabled children. They see him as performing the essential teaching role of training children in tool subjects, passing on the cultural heritage, and encouraging them to learn the facts, concepts, and values of our society. The view of the special educator as just another teacher with an overlay of special understandings and technics is an incomplete one. The special educator has a habilitation role that encompasses much more than the customary subject matter of the various grades and a few special methods to help make this subject matter more accessible to children. In fact, the special educator is a rehabilitation worker of the first importance, with the emphasis being placed upon habilitation.

An article, however lengthy, cannot fully explore the ramifications of this role. As a result, the goal of this paper will be limited to highlighting a few of the special functions of the special educator, above and beyond the common team perceptions of his contribution.

Diagnosis of Experience Deprivation and Provision of Essential Life Experiences

Human development is a consequence of learning and experience. Disruptions in the flow of normal experience lead to disruptions in development. One major cause of impaired experience is disability. When this occurs, it may be expected that certain essential life goals appropriate for the individual at his stage of development will be thwarted. This thwarting will have important consequences for subsequent development. The Committee of Human Development[2] at the University of Chicago has formalized this construct in its concept of the "developmental task."

> A developmental task is a task which arises at or about a certain period in the life of the individual, successful achievement of which leads to his happiness and to success with later tasks, whereas failure leads to unhappiness in the individual, disapproval by society, and difficulty with later tasks. . .

The developmental tasks of young people are much the same for all—disabled or not. Typical ones include learning to talk, to control the physical environment, to along with others, to build a philosophy of life, and to establish career patterns. However, the disability often serves as a barrier to the successful completion of these tasks. Failure to complete them results in retardation and creates a need for remedial and therapeutic measures.

At best, corrective measures do not fully substitute for the original experience. In many instances, "catching up" is difficult, if not impossible. Thus, the habilitation role of the special educator is hygienic and preventive, as well as remedial. In terms of remediation, the special teacher, in cooperation with psychologists and other professional workers, determines areas of living in which the deprivation of experience has occurred. The effects of such deprivation are assessed and therapeutic programs are set in motion to overcome them. As a result, the special educator becomes a diagnostician, uncovering gaps in the life experience of children and establishing programs that, in their cumulative effect, may hasten the development of the disabled child and bring him closer to norms for his age. Such programs include remedial reading and speech, remedial assistance with activities of daily living that should have been learned at an earlier stage of development, and remedial counseling designed to elevate levels of interpersonal relationships to accepted standards.

Many disabled children and youths come to the special educator, having had disturbances in their pattern of developmental tasks. These disturbances may have had their roots in numerous causes. A few are parental and community attitudes; inadequate teaching; long periods of hospitalization, institutionalization, and overprotection; insulation from common activities; and impairments in sensory and mobility capacities. As a result, more than most teachers, the special educator is a specialist in remediation. Without such special assistance, retardation (social-psychological as well as educational) becomes cumulative. Thus, the special educator has the role of stemming the tide of impoverishment of experience and of accelerating learning, so that earlier lacks can be overcome to some degree. The remediation function has much in common with rehabilitation. In concentrated form, it telescopes a series of experiences to effect a rapid change in directions that should have been taken earlier in the normal course of growth. The hygienic function is somewhat different. It focuses upon the here and now. At his present level of age and physical development, the disabled child, as with all children, needs certain current life experiences to maintain himself. For example, he may need opportunities to work and play with others to establish a sense of his own identity and to move forward in the stabilization of his self-concept. Denied these experiences owing to limitations imposed upon him by the handicap, the disabled child may not achieve these essential developmental tasks.

The function of the special educator is to enrich the environment. He must provide the opportunities that other aspects of the student's life ordinarily would but now, owing to the effects of the disability, do not. The teacher of the nondisabled may take for granted certain life experiences as the products of normal family and community interaction with the student. In the case of disabled children and youth, such assumptions are not uniformly tenable. Disability in a child often creates separations and maladaptations in family relationships. Some disabled children lack the physical capacities to reach out for certain experiences. Finally, emotional problems may limit student motivation to interact with the environment. Thus, the special class or school must offer an exceedingly broad range of experiences, leaving little to chance or to the community.

An example of this familiar to rehabilitation counselors is the alleged lack of readiness for vocational planning and adjustment on the part of some graduates of special education. Vocational readiness is the product of a complex developmental process, starting, as far as the school is concerned, with the nursery school and terminating only when formal education terminates. Much of vocational readiness stems from out-of-school activities. The nondisabled child prepares himself through such informal means as carrying out assigned household responsibilities, observing various workers on their jobs, participating in adult-supervised work projects, earning all or part of his allowance through his own services, holding down part-time, week-end, and summer jobs, and ultimately assuming a full-time employment status. These necessary steps are taken by many disabled youths. Among the severely disabled, however, progress through these steps is more difficult. Consequently, in the absence of community and family efforts to create opportunities for work experiences, the special educator must provide them. Often, in cooperation with rehabilitation services, the special teacher develops vocational guidance and training programs keyed to student needs. An outstanding example of this is found in the occupational education and related curricula developed for mentally retarded students.

Developmental Guidance

Rehabilitation practice generally focuses upon individuals who have achieved a measure of stability in their development. The rehabilitation population is often characterized by crystallized interests, full physical growth, and a more or less stable self-concept. Disabled children, on the other hand, are emerging individuals. They are in the process of becoming. Their capacities for growth are substantial. For them, habilitation can be an original learning process, rather than the relearning often demanded of rehabilitation clients. This quality makes for certain implications for the habilitation role of the special educator.

Since habilitation is developmental in character, the special educator is a participant in a process that spans the period of development. This period may extend from early childhood into the adult years. As a matter of fact, special education programs are reaching into the colleges and universities with increasing frequency. Unlike the typical rehabilitation process, habilitation covers periods as long as 15 or 20 years.

Over this period of time, physical, intellectual, and psychological changes associated with growth take place. As each developmental task is completed and the disabled student moves on to the next, new challenges appear. As Barker and associates[3] have indicated, the disability constitutes a permanent and impermeable barrier that cannot be disregarded for any length of time. Thus, among severely disabled children and youths, the disability barrier may serve as a source of frustration and developmental retardation at any point along the habilitation continuum. In rehabilitation, as a result of a relatively brief process, the disabled individual becomes increasingly self-directing and goes on to manage a more or less stable environment with a minimum of additional help. On the other hand, the disabled young person is confronted by a changing self and a changing social status, both of which are subject to the complex effects of disability. As a result, although he achieves an increasing measure of self-direction, the disabled young person requires continuing and persistent developmental guidance.

This guidance is not overwhelming, imposing itself upon the growing organism to perpetuate its dependency. On the contrary, its major goal is self-sustenance. In many cases, this is achieved early in the life of the disabled child and he moves on to meet life demands with a minimum of professional help. On the other hand, severely disabled children and youths, coping with inconsistent social attitudes, shifting demands, and physical, intellectual, and emotional changes, often need help at critical points in their development. This is illustrated by the fact that a number of colleges and universities have found it desirable to offer special guidance services for disabled students. These constitute an attempt to provide continuity of guidance throughout the developmental period.

It is generally held that the teaching role and the therapeutic counseling relationship are incompatible when exercised by the same teacher. Even assuming this to be so, the special educator retains a vital guidance role. This role is expressed through providing essential information, interpreting the world to the child, providing him with reassurance and suggestions, assisting him to understand the human environment about him, serving as an adviser, interpreting his needs to other professional personnel, and serving as a bridge between the school and the parents.

In essence, the special educator is more often a guidance person than are other teachers. He must be sensitive to the guidance needs of the child at every stage of development, provide guidance and instruction at levels within his competency, and refer the student when guidance needs at other levels appear. The referral function brings the special educator into close relationship with members of other professions and superimposes upon him a teamwork role that cannot be ignored by other team members.

Coordination of Habilitation Program

Habilitation and rehabilitation programs are generally complex organizations of services and personnel requiring coordination to insure wholeness, consistency, and mutual goals. In a medical setting, the coordinative function is exercised by the physician. In a state rehabilitation agency, the rehabilitation counselor coordinates the program. Most habilitation takes place in an educational environment. Under these circumstances, the coordinative function falls to the special educator. This is exemplified in the cerebral palsy units found in some public school systems. These units integrate teaching, physical and occupational therapy, medicine, guidance, clinical psychology, and social casework into a single comprehensive service. Generally, special educators coordinate these programs.

In an educational setting, the habilitation program flows out of the classroom. Since the child spends the greater proportion of his time with the special teacher, this endows the latter with opportunities to know him, to understand his needs, and to plan his schedule. In many instances, the fruits of habilitation are first observed in classroom behavior. In addition, the observational and performance data provided by the special teacher are essential ingredients in the diagnostic activities of the team. In some cases, the special educator becomes the team coordinator by default. However, the realities of the educational situation are such that this function would normally be assumed by the teacher.

Thus, special educators fill the coordinative role in habilitation through scheduling, through establishing and maintaining the team's communication network, and through assuming responsibility for the over-all growth of the child. Members of one profession or another often state the case for team leadership's being assigned to their profession on the basis of their unique understanding of the whole person. In a school program, the special teacher can offer similar logic to support his role as coordinator of the habilitation process.

Promotion of Integration Activities

During the first half of the 19th century, special education in the United States was a segregated service. In the beginning, blind and deaf children were invariably educated through residential institutions. Graduation from these institutions sometimes led to a lifetime in a sheltered workshop or an asylum. Since then, American educational values have changed. The goals for exceptional children and youth are integrated ones, wherever possible. Today, even blind and deaf children are being served in the regular public schools, often in regular classes for non-disabled students.

By its very nature, special education is segregative. Even the most modest special education service temporarily removes the child for some period of time from the normal educational environment and, through class placement, equipment, methods, or program, differentiates him from others. In effect, this is comparable to rehabilitation, in which the special environments of the hospital, rehabilitation center, training institution, or workshop are introduced temporarily to effect subsequent adjustment and integration. It is temporary segregation used as a rehabilitative and habilitative device to achieve subsequent integration. Thus, the special educator has the role of promoting integration into normal living through judicious and professional use of a controlled and, to some degree, segregated environment.

Special educators use a variety of educational settings to promote habilitation. These range from highly segregative residential institutions to more integrated public school classes. In a sense, environmental manipulation is a major instrument of habilitation used by special teachers. Disabled children need all degrees of special environment. Some may never achieve full integration. Others, through progressing from one level to the next, may be habilitated into full integration.

The function of the special educator is to use any given educational environment to promote student growth and to prepare him for the next degree of integration. Thus, the special educator holds the key to one of the most significant areas of movement for children and youth. In consultation with physicians, psychologists, and others, they ascertain the degree of integration that is currently most consistent with the individual's needs. Having done this, they proceed to plan and implement an educational program that, in the course of habilitation, will increase student readiness for the next level of integration.

This function has much in common with counseling, the objective of which is to help the counselee to function without further assistance from the counselor. Special education aims at assisting students to develop in such a way that they will require as little future special education as possible. Thus, special educators retain students, not for any fixed period of time, but for only so long as the special education service is desirable. When other settings appear to hold greater promise for student growth, a transfer to them is effected. Thus, the special educator holds a central role in the progress of disabled students toward increasing "normalcy" of educational setting. Since integration into society is a primary goal of habilitation, wherever possible, the special educator is a focal figure in the habilitation of disabled children and young people.

Purveyance of Reality Standards

Many rehabilitation counselors are familiar with certain graduates of special education programs who reveal unreal concepts of the world of work and its demands. These may be expressed in terms of salary level desired, working conditions requested, type of supervision that they believe they should receive, the relationship between speed of performance and quality of product on a job, and the types and degrees of special considerations that should be expected. Frequently there is great disparity between the student's concepts of these factors and the reality of the work situation.

Actually, this is only one area in which reality standards and norms constitute problems for exceptional children and youth and those who work with them. In fact, one of the basic tasks of habilitation is helping the student to share the reality field of the professional worker. Assuming that the frame of reference of the professional worker reflects the societal norm, any failure on the part of the student to recognize and accept it is likely to constitute an additional barrier to effective social relations, vocational success, and mental health.

In effect, the point of discussion is not conformity. In weighing the realities of any situation, the disabled student may decide to conform or not, taking the social consequences that flow from his decision. On the other hand, if nonconformity is built upon a substructure of lack of understanding of the reality, the student really does not have an opportunity to make such a decision. Often, a number of factors combine to shield the disabled student from reality. The attitudes of parents, the social segregation of certain types of educational arrangements, the emotional withdrawal of the student, the inability to move out into the community to test his ideas and capacities, and the admonitions of some physicians and other professional workers may play a part in stimulating unreal thinking.

In some respects, the special educator is an equalizer. His function has come into being because educational opportunities for exceptional children are limited in general educational settings. Thus, a new and more productive educational reality is to be created through which more equal chances will be available. Almost by its very nature, special education is unreal, at least to the degree that it modifies the more common reality of regular school activities. Yet, this unreality may contribute to ultimate handicap. As a result, the special educator takes on the responsibility of functioning in an unreal school environment but minimizing its effects.

The methods used by the special educator are numerous. Educational adjustments made necessary by the disability are kept to the absolute minimum. Those that are made are within the framework of existing general practice. Thus, individual instruction is given the homebound child, but the levels of achievement demanded of him are in the framework of expectations of all students at his level of attainment. Some disabled students may not be able to take important field trips. However, the substance of these field trips is made available to them through vicarious means.

One additional reality-promoting mechanism used by special education is of great importance. Even though special educational adjustments are necessary, as many educational activities as possible are conducted alongside nondisabled students. For example, blind students must use Braille instead of inkprint for reading. Yet, through brailling typical textbooks, it becomes possible for the blind student to attend many regular classes at all educational levels. The mentally retarded are another instance. Even though a special curriculum is required, assembly programs, physical education, and shop subjects may be taken with other students.

Much of the success of subsequent rehabilitation rests upon the reality that the exceptional youth brings with him into the adult rehabilitation process. If this reality is grossly inconsistent with the demands of adult social life and work settings, his difficulties will be multiplied. If, on the other hand, the special educator has been able to introduce a sense of reality into the learning of the student despite the measure of unreality of special education, the odds are more nearly in favor of the student. This reality function influences the success and failure of all other aspects of the habilitation program. As a result, the special educator becomes a key person on the team.

Five habilitation areas were noted above: 1) the diagnosis of deprivation of experience and the provision of essential life experiences; 2) developmental guidance; 3) coordination of the habilitation program; 4) promotion of integration activities; and 5) purveyance of reality standards. These areas have important implications for the functioning of the special educator on the (re)habilitation team. As such, they are a concern to professional workers everywhere who serve exceptional children.

Factors Affecting the Special Educator Functioning on the Rehabilitation Team

It is suggested that the special educator has an essential role to play in habilitation, that he will be a member of the habilitation team, and that we should explore means of working closely with him. Some of the implications in this connection are presented below.

Recognition of Status

Effective team cooperation with special educators requires a recognition and acceptance of their status. Tolerance of their presence will no longer suffice. It is essential that they be recognized for what they really are: trained specialists in general and special education, with a unique role to play in the habilitation that does not duplicate or broadly overlap the roles of other professionals. In general, they have one capacity that no one else on the team possesses. They are the most competent individuals in the art and science of teaching.

It almost seems to be redundant to note this. Yet, in many instances, this special area is either ignored or overlooked. For example, educational and clinical psychologists, on the basis of their findings, tend to tell teachers how to teach a child. Not infrequently, special educators find these suggestions totally unreal and impractical. Furthermore, these specific instructions constitute a lack of appreciation for the skill of the teacher. The teaching capacities of psychologists would soon become apparent if they spent a week or two in the classroom with the children, as teachers do. Respect for the teaching profession is manifested through making available to them the best data we can submit. Then, teachers are capably trained to make essential curriculum and methodological decisions. At times, physicians, counselors, and social workers are guilty of the same practice of telling how to teach the child. Effective teamwork with teachers can best be built upon mutual respect for professional competence. Usurping their function is potentially damaging to the student and to the special teacher's maximum contribution to the team.

Better Habilitation Training for Special Educators

Some special educators perceive themselves as having inferior team status. In part, this is due to the reactions of other professionals to them. However, some measure of it results from their own inadequate preparation for the teamwork function. In this regard, teacher training institutions can improve the preparation of special educators by: 1) providing courses that specifically instruct in habilitation functions; 2) being increasingly selective in admitting candidates to this exacting field; 3) providing special teachers with training in group dynamics and teamwork; 4) exposing special teachers to teamwork situations with other disciplines. For example, at Teachers College, Columbia University, some special education students take one or more interdisciplinary rehabilitation courses.

Eradication of Artificial Lines Separating Special Education, Habilitation, and Rehabilitation

Currently, rehabilitation as practiced in state agencies reaches down to age 14. Special education reaches up to the completion of formal education, but no farther than the termination of graduate study. Habilitation is still an amorphous term that has no official status and is used to describe a variety of different situations. Through custom, legislation, and concept, the three terms—habilitation, rehabilitation, and special education—tend to connote three different aspects of human service although the areas cannot be precisely identified.

As a group, special educators have tended to identify themselves as educators rather than as rehabilitation workers. This position is valid, but partialistic. The earlier discussion on the habilitation role of the special educator suggests that, in addition to the basic teaching function, special educators are also rehabilitation specialists. Their concern with medical problems, comprehensive habilitation programs, interdisciplinary teamwork, coordinated community efforts, and the broad area of student adjustment brings the special educator into the area of rehabilitation. He straddles two major fields, with one leg firmly planted in rehabilitation.

On this basis, the line between special education and rehabilitation blurs. This is not unique. Physicians are similarly concerned with diagnosis, treatment, education, and research, as much as they are with rehabilitation. Many professions straddle several fields, with rehabilitation as one of them. Insofar as special education participates in the rehabilitation process, it is a rehabilitation profession. Perhaps the time is not long coming when special educators will more frequently perceive themselves and be perceived as rehabilitators. For example, it would be appropriate to see a special education section in the National Rehabilitation Association and other professional rehabilitation groups. Just as special education in its teaching aspects is a special instance of general education, so is it in its habilitative aspects a special instance of rehabilitation. It is felt that the eradication of these artificial lines will have the practical consequence of better integrating the special educator into the rehabilitation team and making rehabilitation service available to all, regardless of classification by age.

The differentiation between the terms rehabilitation and habilitation is sound. Semantically, it would be operationally more useful if both rehabilitation and habilitation were components of a larger term that would be inclusive of both. However, this is not the case. The more general term is rehabilitation. Habilitation is a specific limited instance of rehabilitation. Since the term rehabilitation is likely to endure as the comprehensive term by reason of its place in legislation, the literature, and commonly accepted concepts, it would seem that, for most practical purposes, it should be used with persons of all ages, whether they have ever been nondisabled or not.

There was a time when the "re" in rehabilitation had a sharp meaning. It indicated the need to return an adventitiously disabled person to an earlier nondisabled status. This meaning has long since been obliterated. The goals of rehabilitation are not restorative in the narrow sense of the word. In many instances, the objective is helping the disabled person develop a new pattern of living. Many workers in the field recognize that there is no turning back. The experience of being disabled creates many lasting changes in human circumstances. Often there is no return to the past. The problem is that of finding a new way of life. Some of the components of this way of life may be threads of the premorbid pattern, but essentially the configuration is a new, and hopefully, satisfactory one.

Except for technical discussions, it would seem wise to blanket habilitation and special education under the term rehabilitation. Some movement in this direction is already evident. For example, the term rehabilitation is now widely used in reference to children. Furthermore, the title of the bibliographical magazine in our field is *Rehabilitation Literature,* covering all age groups and settings. In concept as well as in words, it seems advisable to perceive all special educators, habilitators, and rehabilitation workers as participants in a single field, a field that serves exceptional persons of all ages and that is bound together by the philosophy of rehabilitation.

Development of Rehabilitation Legislation for Disabled Children and Youth

Currently, federal and state rehabilitation legislation does not apply to children and youths under age 14 or 16. This legislation has imperfections, but it also has exceedingly positive aspects and a great promise for the future. Efforts are now underway to amend the federal law to broaden and deepen its impact upon rehabilitation in general. Whatever shortcomings this legislation may have, it has the merit of providing consistency, funds, and structure to the rehabilitation efforts of the several states.

On the other hand, legislation for disabled children is a patchwork of federal, state, and local enactments without apparent order or direction. As far as the educational aspects of special education are concerned, the leadership of the U.S. Office of Education and the state departments of education is satisfactory. However, the rehabilitation aspects of special education are subject to varying provisions and administrations. Often, crippled children's acts, departments of health, departments of welfare, social security agencies, and others contribute to a sprawling and not altogether complete service.

Disabled children need rehabilitation service. They can benefit from physical restoration, vocational guidance and training, assistance with the activities of daily living, scholarships, research, and other related services. These are comparable in many respects to the rehabilitation services provided to adults. As a matter of fact, we already have evidence of the value of a coordinated rehabilitation approach to exceptional children. Some state rehabilitation agencies have comprehensive programs for students in secondary schools. These programs have served as invaluable adjuncts to the special education offerings at this level.

Until now, the rehabilitation emphasis has been upon adults. In the face of the current need, there seems to be persuasive evidence that additional legislation dealing with the rehabilitation of children would be exceptionally helpful. As time goes by, it may be expected that national and state agencies will be giving additional thought and study to this possibility. At this point, disabled children and youths who could benefit from integrated rehabilitation programs supported by public funds are not always obtaining these services. The legislation that has worked so well for out-of-school disabled persons seems to hold promise for children and youth, as well.

From an examination of the habilitation role of the special educator, four implications have been drawn for rehabilitation practice: 1. Special educators have a need for recognition and status on the rehabilitation team. 2. They have a need for better training in the area of habilitation. 3. It is desirable to eradicate the artificial lines separating special education, habilitation, and rehabilitation. 4. Service to disabled children and the contribution of the special educator will be enhanced by the development of rehabilitation legislation for disabled children and youth.

Through better integrating the special educator into the rehabilitation team and making it possible for him to have more effective tools, we can all contribute to the improvement of service to disabled children and youth.

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Significance of Public Attitudes in The Rehabilitation of The Disabled

G. ALLAN ROEHER, Ph.D.

Summary

The failure of persons who have disabilities to function as socially normal persons is rooted in society's negative attitudes and emotional reactions. The prevailing attitudes that determine social expectations and treatment strongly influence personality. When individuals perceive disapproval and rejection because of a disability, their behavior moves away from the social norm toward extremes of withdrawal and aggression.

The reluctance of social agencies to make attitudes toward disability a priority minimizes the positive effects of physical rehabilitation. The dominant sympathetic and charitable view of persons with disability can be displaced by an "equal-status" viewpoint, however, if there is increased social contact between people with and without disabilities, education, legislation, and even psychotherapy. Rehabilitation agencies that encourage volunteer activity, integrate clients within their communities, and reject stereotyped emotional fund-raising appeals will influence the attitudes that limit psychosocial development in persons with disabilities.

IN SPITE OF INTENSIVE application of rehabilitation services, we fail in our efforts to habilitate, or rehabilitate, adequately countless numbers of disabled. Using the measure of success as the extent to which these individuals subsequently function as *socially normal* persons (except for actual residual physical and mental limitations), many fail to realize their potential. Varied reasons can be, and are attributed to: their lack of motivation; inadequate opportunity to prove themselves; limited acceptance by society; or asocial personality and behavior traits—all by-products of adverse environmental forces. The problem is not one of physical neglect or inadequate treatment resources but is much more deep-rooted in the negative attitudinal and emotional reactions of society toward its handicapped members.

Tenny[1] succinctly expresses the problems facing the disabled in terms of *limitations* as: limitations imposed by functional loss due to the physical impairment itself; limitations imposed upon the handicapped person by society; and self-imposed limitations of withdrawal or aggression resulting from the handicap and society's attitude toward it.

The diverse and extensive services mobilized within the framework of the modern rehabilitation movement are designed essentially to overcome the limitations of the physical impairment itself. To the extent that physical deformity has been corrected, individuals have been removed from their minority status in society. Even though function has been improved, perhaps to the point where economic independence is potentially feasible, those still left with visible impairment behave and react differently to their problem. For them there seems to be a lack of correlation between physical and mental potential and their ultimate level of function as self-sustaining members of society. Certain persons, for example, with slight disabilities become totally dependent and resigned to an unproductive life, while others with greater physical disabilities achieve independence and frequently an unusual degree of

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success. It would appear, therefore, that like defects do not produce similar types of maladjustment and degrees of dependency, and it may be hypothesized that the difficulty does not stem from physical causes alone.

Social scientists observing the situation have ventured a theory to explain the cause as social. Man is a social being whose behavior depends on the nature of his social contacts.[2] The modern sociological concept views disability to a large extent as a function of cultural and social factors. The nature and degree of handicap, in the final analysis, are based on cultural definitions and social perceptions and are so interpreted to the disabled person by the people with whom he associates. The basic social process is interaction, whereby an individual learns how to become an accepted member of society and about the standards of behavior expected of him.

The Attitude Concept

The constellation of cultural judgments regarding an individual or a group of persons and the standards of behavior expected of them are made manifest by a psychological entity known as *attitude*.* The ways of looking at things and persons, forms of readiness, approaching and withdrawing behavior, feelings of rightness and wrongness, and liking or disliking objects or values are all geared to the usual working concept of attitudes.[3] The concept is coterminous with such other psychological constructs as interests, appreciations, motives, mores, morality, morale, ideals, prejudices, fears, sentiments, and loyalties. "From the point of view of the individual, attitudes constitute the individual's own evaluation of his conduct and desires in relation to the system of social values as he understands them."[3]

The Effect of Negative Attitudes on Disability

Prevailing attitudes, as has been indicated, determine the social expectations and treatment accorded an individual in society. Such treatment determines personality. Normal treatment by society produces normal personality, exceptional treatment exceptional personality.[4] The physically handicapped individual is profoundly influenced by society's indication as to his role and status of behavior. Studies show that the self-image of the handicapped child often is a reflection of social stereotypes or a reaction to them; rejection, for example, produces inferiority, self-consciousness, and fear. Crippled children compare themselves unfavorably to other children. The individual perceives himself as incompetent, distorted, and unacceptable, yet he is forced continually to "live with himself" with the cognizance that there is no escape.

Hentig[5] postulates that, aside from perception of the mechanic disability, the individual's eventual "self-image" is the product of a three-stage mental reflection through: 1) inspection of one's own defects, 2) suspicious interpretation of facial expressions, actions, and words of associates, and 3) the accumulation of impressions as to other people's attitudes, both true interpretations and misconstructions, regarding disablement.

The consequent manifestation of this maladjustment is withdrawal, which may assume many forms. Religious "cushioning" of the feeling of inadequacy, for instance, is one form in which the compensatory rationale may be a notion of moral superiority, future recognition, and reward. Fanatical withdrawal is another form, possibly a way of seeking attention; securing praise (for modesty in bearing misery) may be another means of gaining recognition and perhaps affection. Another form of withdrawal is identification with one's own kind.

Hentig explains the dynamics of progressive behavior as follows:

> Being treated as an outsider the disabled establishes himself as an outsider, he retreats from the world of duties since some rights are denied, he slips into that minority complex in which people feel perfect and superior because they are maltreated and misused. Emotionally a satisfying compensation, the attitude is no adequate adjustment to the forces of reality. The mental balance is not squared but thrown into greater disorder.[5]

Behavior in the other extreme, namely, aggressiveness, also occurs. Here the defect has an activating effect and the individual grows extremely competitive, to the point where he refuses to admit he is incapacitated in any way—a wishful amnesia or bravado attitude that is sometimes useful in rehabilitation if carried through.

It is necessary to distinguish between children and adults in describing the social-psychological position of physically disabled persons. The negative attitude of society envelops the child in a vicious circle: "He is handicapped, society sympathizes, over-protection results, the child feels over-protected in terms of what he sees society doing for his non-handicapped friends, he feels frustrated."[6] As the child's world expands beyond the family limits, disadvantageous forces may begin to operate. Because he is disabled, less may be expected of him and he may be unnecessarily helped in many ways. The psycho-

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*Since a satisfactory eclectic concept of the term *attitude* does not exist, the arbitrary one generally accepted in the measurement field is used: An attitude is a disposition to evaluate certain objects, actions, and situations in certain ways.[17]
The term *prejudice* is used as meaning an adverse or negative attitude toward a group of people in society, based on preconceived judgments about individuals, without just grounds or sufficient knowledge of the facts.
Disabled and *handicapped* are other general terms to which various meanings and interpretations are attached because of the variability in degree and type of impairment among individuals. No differentiation is made between the terms. There is support for this approach in the findings of two major attitude studies. Force[7] found, "There was enough evidence of the influence of physical condition on choosing to infer that there was early and continuous minority group identification, based apparently on the label 'handicapped' . . ." McBride[24] found little or no consistency in an individual's attitudes toward such various disorders as cerebral palsy, tuberculosis, blindness, deafness, facial disfiguration, and poliomyelitis.

logical results of constant help are varied but may contribute to loss of self-esteem and ambition.

A study by Force[7] revealed that few physically disabled children have enough positive assets to offset completely the negative effect of being labeled handicapped by normal peers. However, he found that, "The individual physically handicapped child who is highly accepted by a peer group manifests many socially desirable traits and relatively few negative traits of behavior patterns."

When the child becomes an adult, he faces, in addition to the family and the clique group, a rather well-structured social status, which is variously underprivileged, ambiguous, and marginal.[8] When the gap of social distance seems too great to bridge, some retreat to a more tolerable psychological situation—a phenomenon well recognized in psychology. Others go in quest of groups in which a common wrong, real or imaginary, has abolished social distance, such as social groups for the adult handicapped. The self-imposed limitations of withdrawal or aggression are, therefore, a by-product of the handicap itself and society's attitude toward it.

Certain members, in spite of continuing residual disability, succeed in bridging the social distance between themselves and others in their environment. Through "supreme exertion they gain admiration and recognition and establish, thereby, blessing, social proximity, and warming contact."[5] Others, unable to reduce the social distance, develop defense mechanisms that manifest themselves in the logical categories of "fight" or "retreat."

The Effect of Negative Attitudes on Rehabilitation Programing

Administrators, supervisors, and other workers in the field have given only occasional and relatively superficial attention to the matter of a suitable social climate for the handicapped in society. However, as necessary facilities and staff reach the stage of even minimal adequacy and, as the files of the mildly involved and highly motivated segment of the caseload are closed as "rehabilitated," agencies are becoming increasingly concerned about the residue: persons with seemingly positive prognosis whose progress is stagnant.

One of the most perplexing of all rehabilitation challenges, and one entailing the greatest per capita expenditure with consequent disappointing results, is the rehabilitation of the brain-injured, specifically the cerebral palsied. A number of writers[4, 9, 10] and many therapists designate the influence of society's lack of understanding, interpretation, and reaction as contributing to the tensions intensifying this group's problems of inco-ordination. Rehabilitation organizations may have inadvertently added to the problem with the modern sympathy-oriented type of fund raising.

The effect of the persistent emotional appeal in fund campaigns could well have changed the former apathetic views to sympathetic attitudes. Related literature and practitioners in the field advance many arguments casting doubt on the contention that the public's increased willingness to provide rehabilitation services does, in fact, represent a revision to a positive attitude. In the practice of rehabilitation, many incidents occurring through public contact bear out the premise that there is continued lack of understanding and positive acceptance. Typical incidents involve the employer who donates generously to fund appeals but refuses to employ the disabled and the volunteer who, on visiting a crippled children's camp or treatment center, expresses amazement at the low proportion of severely impaired persons—revealing a perception of disability quite negatively distorted from the real situation. Through depersonalized charity, the general public has apparently been conditioned to envision crippled children as pathetic, helpless creatures warranting sympathy and charity.

Reasons for Neglect of the Problem

If the aforementioned is the way in which disabled persons solve the problem of social distance, should it not be apparent to administrators and workers in rehabilitation that minimizing the social crisis of the disabled is tantamount to, if not more significant than, the provision of many ancillary rehabilitation measures? It seems paradoxical that, in comparison to the monumental achievements in physical restoration, agencies have, in general, failed to develop effective programs for changing public attitude and that rehabilitation organizations have not been induced to allocate funds for experimental work in modifying the problem.

Various reasons can be advanced for the paucity of objective understanding of the problem and the lack of educational and action programs. Workers and administrators in rehabilitation, absorbed with specific treatment problems, tend to shy away from theoretical investigations as impractical luxury. An assumption also may be that in recent decades attitudes toward the disabled have already undergone significant positive changes. There also is the defeatist attitude. The argument involved here is based on an assumption that attitudes cannot be changed, and, therefore, complete dependence should be placed on perfecting rehabilitation processes. Unfortunately, many disabled will continue through life with obvious limitations, and reliance on improved rehabilitation technics as the total answer is an unrealistic approach—at least for the foreseeable future.

The magnitude of the problem, moreover, makes it untenable to adopt a defeatist proposition that nothing can be done. There is also an ethical responsibility to the disabled and to the public, who have entrusted vast sums of money for alleviation of the problem. This responsibility implies constant evaluation of the effectiveness of current programs. If this is carried out, the matter of change of public attitude will obtain higher priority than it has in the past.

Status of Attitudes Toward the Handicapped

Former Attitudes.—Literature dealing with social attitudes suggests that emphasis formerly rested primarily on the disabled's passive role of receiving help, without thought of extending encouragement and opportunity to assert himself and to assume interpersonal and community responsibilities.[11] Kessler sums up former attitudes in terms of two great social barriers: psychosocial and economic prejudice and prejudice resting on superstition, misunderstanding, and false concepts of capacity to work.[12]

Current Attitudes.—In general, social consciousness is now better developed than in the past, with resultant provision of necessary treatment and ever-expanding opportunities for economic usefulness. Physical disability, however, still magnifies the difficulties of the individual in achieving social acceptance by normal peers. Contemporary society, it is generally agreed, accords the handicapped a sympathetic, charitable, rather than equal status, but variations in cultural definitions and impairments occur within and between family and community settings.

A review of history indicates that societal perceptions and definitions of the handicapped are neither homogeneous nor static. A study by Hanks and Hanks[13] compared the status accorded the physically handicapped in a number of nonoccidental societies and found wide differences. Some cultures completely rejected the handicapped and they became outcasts; in some, they were treated as economic liabilities and grudgingly kept alive by their families; some tolerated and utilized the disabled in incidental ways; in other cultures, they were given respected status and allowed participation to the full extent of their capability. The authors emerge with three hypotheses about social attitudes toward the physically impaired.

> Protection of the physically handicapped and social participation for them is increased in societies where: 1) the level of productivity is higher in proportion to the population and its distribution more nearly equal; 2) competitive factors in individual or group achievement are minimized; 3) the criteria of achievement are less formally absolute as in hierarchical social structures and more weighted with concern for individual capacity, as in democratic social structures.[13]

Similarity with Other Minority Groups

Much of the literature about current attitudes assumes that the physically disabled are subjected to societal attitudes similar to those other minority groups face. Similarities do exist among the handicapped and other minority groups who are such by virtue of race, creed, or nationality in that all: produce social distance; are unfavorably portrayed in literature, drama, and "slapstick" humor; face segregation, particularly in schools; and suffer vocational disadvantage (over and above that involved in the nature of a handicap).

Differences, on the other hand, must be considered: Unlike in other minority groups, the minority status of the handicapped child differs from that of such an adult; family and neighbors do not share the minority status of the handicapped; the handicapped lack the support that comes from home and neighborhood proximity to other handicapped; there are few communities of the handicapped; children who are handicapped do not receive from their home and neighborhood a tailor-made reaction to prejudice and discrimination but must face the majority attitude alone; the handicapped are not alike in their minority status (vary with differences such as in classification, degree of involvement, obviousness); the handicapped do not create social-crises threats.[1]

Formation and Change of Attitude

Development of attitudes.—In the field of social psychology, views are varied as to the concept of attitudes and the elements influencing change in attitude. The notion that attitudes are innately determined or that innate factors are associated therewith is generally discounted by writers. The only suggestions supporting logical argument deal with the possibility that certain specific attitudes depend upon so-called innate temperamental traits; the intensity of an attitude may be related to possibly innate emotional tendencies, and, occasionally, an attitude may be conditioned by one's own physique.[14] Contemporary theories commonly hypothesize that attitudes are learned, beginning in infancy as original drives and overlaid by social experience.

Most of our attitudes (and prejudices) are derived in childhood. The youngster acquires them from parents, playmates, teacher—usually accepted as "factual" information, since children have no reason (or lack knowledge and experience) to doubt remarks made by peers or elders, statements made in literature, or things depicted in motion pictures. Formation of attitude and prejudice need not be on a rational basis.

Pressures toward conformity within a group or society influence development of attitudes in the individual directed toward the mean attitude in the population. Individuals have an innate desire to conform or accept views of those with whom they identify. This makes for agreement with, and acceptance by, others. It is easier to conform than to resist the values of the group. Hence comes the tendency to behave and believe as the group does—and the tendency to reject or resist information contradicting the group opinion. These largely subconscious phenomena become fixed personality traits—usually resistant to reason. This craving for security impels the individual to have an attitude on any decisive issue and requires that this attitude be of a stability corresponding to the nature of the situation to which it refers. The individual then protects this attitude from being undermined by thought or perception processes.[15]

Goldberg supports this premise with his hypothesis that, when factual answers cannot be found or when the answers pose a threat to emotional security, an individual fabricates answers and distorts information so as to reinforce the attitude he has already established, whether conscious or not.[16] Prejudice within the individual may manifest itself differently in private life than in the group—because of the need for group identification.

Although among social scientists concepts differ concerning formation of attitude, they have certain points of agreement: attitudes are not inherited; the learning process plays a major role in their development; attitudes involve problems of perception and motivation; people may act contrary to their attitudes.[17]

Stability of Attitudes.—It has been proved and generally accepted that certain attitudes within the individual change. Attitudes toward product preferences, politics, style in clothing, unemployment, labor unions, and the like can and do change quite readily.

Agreement is less conclusive in the area of change of social attitude in religious and ethnic prejudices, particularly where minority groups are involved and the prejudice is negative, that is, where the attitude serves to place the object of the attitude at a disadvantage. Prejudicial attitudes of this nature, though always modifiable, are much more resistant to fundamental change.

Prejudice toward minority groups is a complex phenomenon. Authorities who have studied the problem[18, 19, 20] recognize such contradictions as: group hostility thriving very well alongside friendly, even intimate relations between individuals of two hostile groups—the accepted individual being considered an exception to his group; persistence of prejudice in the face of contradictory facts and radically altered social situations; and, in some instances, reversal of modified attitudes to their original form—people whose behavior has been changed through psychological manipulation lapse into old ways as soon as the agencies of manipulation are removed.

Modification of Attitudes.—Social scientists agree, and the results of studies corroborate, that a number of ways are effective in changing public attitudes as they relate to the minority group described as the "handicapped." The most effective is through intergroup contact or interaction. When prejudiced people are brought into direct contact with minority group members and share experiences with them, attitudes often undergo a gradual but deep change. Familiarity with the attitude stimulus diminishes unconscious fear of the unknown, since such fears are often unfounded and based on ignorance. The closer the relationship between the handicapped and others, the greater the potency of such relationships in the formation or change of attitudes.[3]

Direct educational programs are a second way of changing attitudes. Familiarization with accurate information can contribute directly to an amelioration of the cultural atmosphere in which undesirable attitudes breed. Again, this tends to dissipate fear of the unknown or the uncertain.

A third way is through changing the attitudinal environment of the prejudiced individual. As stated earlier, people desire to accept the views of those with whom they identify. A person seeing others around him changing their attitudes is relieved of vague fears and can change with them. If, therefore, a prejudiced person is in a situation where people important to him are free of prejudice and express this, he may change without being aware of it.[21] Thus, people who enjoy prestige in the eyes of the conformist can effect a change, particularly if their statements are backed by action and not contradicted by other people of high prestige.

While contacts that provide knowledge and acquaintance engender sound beliefs and hence contribute to reducing prejudice, the effect of the contact depends upon the kind of association involved. True acquaintance tends to lessen prejudice. The more sustained the acquaintance, the less the prejudice. Those having closer contact perceive less difference than those who are farther away. On the other hand, casual contact may leave matters worse if participants are motivated to associate with the handicapped for such unrealistic reasons as sympathy or vague fears. Only the type of contact that leads people to *do* things together is likely to bring about positive results.[20] The acceptance of the handicapped is greater in war-torn countries where the physically maimed are seen in greater numbers and enter into the social life more than they do in North America.

Legislation against discrimination is another possible device but is probably only indirectly effective in that it creates an atmosphere discouraging the development or practice of prejudice. Laws, however, can create situations that stimulate change in existing prejudices or discrimination.

Psychotherapy is yet another way of effecting change in attitudes. While this is an important individual approach, it is not, at least currently, adaptable to large-scale operations.

Experimental Studies Relating to Change in Attitude

By comparison with research relating to attitudes toward ethnic and religious groups, relatively few studies have been reported that attempted specifically to measure change in attitude toward the handicapped.

Kvaraceus[23] investigated the attitude (acceptability) of professional workers—mostly teachers—toward various disabling conditions in relation to their knowledge of the conditions. Results revealed a strong preference of the respondents for teaching those groups of disabled about whom they believed themselves best informed.

McBride[24] measured attitudes of the public toward epileptics relative to attitudes toward other disabilities. An experimental group was given information on epilepsy, but the results were not significantly conclusive. Granofsky[25] conducted a controlled before-and-after experiment attempting to change underlying attitudes of the nondisabled toward disabled war veterans by an induced social contact experience. Again results were inconclusive. The authors of the latter two studies imply that the indecisive results may be due to the nature of the sample selection and the measuring tools used.

This writer conducted an extensive investigation to measure differences in attitude according to extent of accurate information held about, and degree of personal contact with, disabled persons.[26] Findings revealed significant mean attitude score differences among groups. The principal conclusions were that social contact between the nondisabled and disabled and increased factual knowledge of the disabled lead to a more generalized tolerance and fundamental acceptance of handicapped persons.

Practical Implications to Rehabilitation Workers and Agencies

If, as the dominant conclusions suggest, the essential ingredient in modifying social attitudes is interaction of disabled and nondisabled, what practical implication does this have for the professional agency and rehabilitation worker?

For the rehabilitation agency this points to active, direct participation by the public in rehabilitation programs. Paradoxically, rehabilitation programs have tended to dissociate the public (especially the volunteer) from the client. There seems to be mounting resistance to use of volunteers in direct program function and a seemingly dogmatic intolerance of their participation on the part of professional workers. Increasingly, volunteers are relegated to the sole function of fund raising and like tasks that isolate them from the client. The rationale behind this resistance is that volunteers, though with good intentions, disrupt programing and cause undue psychological trauma to the client. This argument is too often exaggerated—merely reflecting a deterioration in the art of professional leadership in use of volunteers. Organizations that properly screen, orient, and supervise volunteers attest to the value of volunteer programs, even to involvement in very direct treatment or program situations. The benefits to be gained from more direct lay participation far exceed the limitations. Such a sound volunteer program is not developed without cost and effort. Its success depends on the allocation of adequate funds and assignment of qualified, competent staff.

Some agencies have been eminently successful in mobilizing the lay public and assimilating their activities into rehabilitation programs. The volunteer visiting programs to mental hospitals have been a deliberate attempt by organizations to change the social climate for the post-treatment psychiatric patient. Such groups are cognizant of the relative futility of psychotherapy in the face of rejecting public attitudes. Other agencies assign volunteers to "staff" functions, as in camping and regular recreational activities. Too frequently, however, activities relegated to the volunteer include showering sympathy on the handicapped by providing gifts or delicacies for a party. The atmosphere of such activity serves only to reinforce the existing negative attitude stereotype, as against the other approach in which the volunteer is placed in a setting that makes demands on him to treat the handicapped in a manner consistent with agency principles of treatment. In the latter instance, the effect is a modification of attitudes within the agency's corps of volunteers, manifested not on a one-to-one basis but in terms of geometric progression. The modified attitude of one individual influences his family and friends, who in turn influence others in a rapidly multiplying fashion.

The professional rehabilitation worker, then, must avoid the tendency to isolate himself and his work activities from the public. The clinical environment of the rehabilitation setting must expand to include actively more facets of community life. The public can be involved in a variety of ways, limited only by the imagination, resourcefulness, and desire of agencies. Planning and developing programs utilizing resources for normal persons is one approach. This is in contrast to the recent trend of building special and isolated facilities—a situation that would have developed in a more balanced manner had the problems of the handicapped been envisaged in total perspective. If the adult handicapped is expected to live in a normal environment, he should, to the extent possible, be conditioned during his formative period in such a setting. By analogy, society also needs an opportunity to learn to accept and adjust to the situation.

Finally, rehabilitation organizations must protect against undermining the constructive results of their program efforts. Voluntary agencies are in danger of allowing fund-appeal publicity to contradict the philosophy and efforts of their treatment programs. Agencies must resist the pressures of the promotion man, fund-raising director, or service clubs to use stereotyped "tear-jerking" pictures and slogans as the media for extracting public financial support. Granted, pressures are tremendous on an agency to resort to such a device—competition from other appeals, cost of campaigns, the fact that the device is so simple to employ and that good results can be obtained despite weak organizational structure. Good and adequate results can and are being obtained without these devices by agencies concentrating on strong community programs, using its volunteer work force in a constructive manner during fund-raising periods.

These comments should not be construed as an attempt to oversimplify the problem, or rather the solution. The issues involved in attitudes of society are extremely complex regarding the disabled and shifts in technic and agency programing must, of necessity, be gradual. This is an area that rehabilitation organizations, particularly voluntary, should seriously consider as presenting a major unmet need and as a challenge in the coming decade.

With the rapid growth of physical rehabilitation resources and with official government agencies assuming more and more responsibility for the financial operation of services, private agencies are increasingly being relieved of much financial and program responsibility. This means a gradual shift in program for many agencies, leaving funds available for evaluation of unmet needs and research into technics to combat unsolved problems. High priority should be given the surmounting of psychosocial barriers confronting the handicapped.

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The Role of Religion in Rehabilitation

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Summaries

Part I

Determining whether religion has a place in rehabilitation is complicated by the variety and degrees of religious faith. Individuals' reactions to and choices about their disability are affected by the nature and depth of their beliefs concerning personal dignity and independence. While it is generally agreed that Judeo-Christian principles motivate rehabilitation programs, opinion varies widely about the appropriateness of religion in rehabilitation and the relationship between a therapist's religious experience and professional effectiveness.

Part II

Many people who develop a disability relate an eventual strengthening and commitment to religious beliefs. Clergy and health professionals observe that traditional religion and existential therapy influence patients' thoughts, feelings, and adjustment. However, the respective roles of clergy and psychological counselors during treatment are unclear. The proper role of religious institutions is also in question. Major topics for additional research include the role of religious and secular counselors, the significance of religion in rehabilitation, the relationship between the intensity of belief and the belief itself, and the best uses of religious concepts in rehabilitation.

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Part 1 of Two Parts

MUCH HAS BEEN WRITTEN recently concerning the responsibility of churches in regard to exceptional persons. Books, study guides, and countless articles in denominational and interdenominational journals give evidence of the increasing concern of churches for the exceptional person in the congregation and in the community. This is an appropriate time to consider the role of religion in the rehabilitation process.

Growing out of the increasing trend toward professional specialization in increasingly narrower areas and the emphasis on the need of the "team approach" is an awareness of the need to synthesize the findings and contributions of the various specialists. The possibility is being suggested by more and more writers that somehow, in analyzing and specializing, we have lost something. Discomforting though it may be in the midst of our elaborate programs, we encounter the question: Do our present rehabilitation programs recognize and seek to meet all of the needs of the "whole man"?

From this background there arise such questions as: Does religion have a role in the rehabilitation process? What can religion contribute? What can it contribute to the individual patient or client, to the doctor or therapist, to the rehabilitation program?

In seeking answers to these questions, generous help was provided by the 31 persons whose names are listed in the bibliography under the heading *Personal Correspondence*. Of these 31 correspondents, 8 are "church-related" (1 rabbi, 1 Catholic chaplain, and 6 employed by church-related institutions); 6 are connected with national health organizations; 4 are associated with state or federal organizations; 5, with universities; 5, with rehabilitation centers; 1, with industry; and of 2 it is known only that they are disabled (a designation they prefer to handicapped or exceptional). In addition, 27 books, 12 pamphlets, 53 articles, and a number of privately published lectures, as well as other special materials, were studied.

Although many of the biographies of handicapped persons make interesting reading, it is doubtful if many of them are of any significant help either to persons who are handicapped or to those who are seeking to help the handicapped. There are references to the motivation, comfort, and courage found in religious beliefs and practices; there are descriptions of the physical assistance and encouragement provided by religious groups and individuals; and there are references to the "spiritual enrichment" gained by the handicapped person and his family; however, it is often necessary to read many pages to find an informative account of a few significant incidents. For this reason, it is from personal correspondence that this article draws most heavily.

The questions raised are not fully answered in this article. Some of the correspondents, instead of providing definitive answers, emphasized the complexity of the questions and opened unexpected avenues to be explored. Furthermore, research in these areas is almost nonexistent. It is hoped that this article will stimulate interest and provoke further research in some of the specific areas that will be indicated.

The need for exploration and research to clarify certain issues was expressed by several correspondents. Whitehouse[29] believes that such exploration would be profitable both to "those who organize and foster religious practices" and to "those who work directly in the rehabilitation field." The former might be stimulated to greater effort, and the latter might gain "an appreciation of the motivational forces of religion" and "the therapeutic resources of the clergy and church-sponsored projects."

Definitions and Limitations

The first difficulty encountered was in the definition of terms. For the purposes of this article rehabilitation is thought of as the "cultivation, restoration, and conservation of human resources." Whitehouse,[137] in proposing this definition, stated that the goal of rehabilitation is the "maximum utilization of our human resources," which involves cultivation and conservation as well as restoration.

> Man is a whole person. His mind and body are one. What affects one part of him affects all of him. His disability is but one of a number of influences. Treatment should be as total, fundamental and dynamic as possible to keep apace with individual and environmental changes. . . . Man requires the exercise of his mind, body, and spirit. If he does not use his abilities adequately and constructively, deterioration occurs with consequent evil effects.

It is in this inclusive sense that the term *rehabilitation* is used in this article.

Religion has been defined in many ways. Even if for this discussion *religion* is restricted to belief in a supreme being (involving attitudes of devotion, reverence, and gratitude along with the desire to obey and serve), there still remains too wide a variety of beliefs and attitudes to be considered adequately here. If discussion is further limited to the Judeo-Christian concepts that predominate religious thought in this country, there is still a staggering diversity.

For example, there is considerable evidence suggesting that some sects or denominations are more "guilt producing" than others. Some denominations have many more "thou-shalt-nots" than others have; some sects have issued official statements of positions or beliefs, and members must accept them; some denominations have adopted official positions, but the individual members are free to accept or reject them; still other denominations have issued no official pronouncements on some questions that are important in rehabilitation. Furthermore, the belief of any member of a given religious group may differ from the "official position" or doctrine of the group, and, indeed, the activating, decision-making belief of an individual may differ from the beliefs he openly professes.

A small measure of this diversity is illustrated by the answers given to a question almost inevitably raised in connection with any handicapping condition: "Why did this happen to me (or to my son, to my wife . . .)?" At least five answers were given by members of *one congregation! 1)* God did this as punishment. *2)* Because God loves me, he has given me this "cross to bear for him," and I must bear it gladly (proudly or uncomplainingly) without letting it hamper my spirit. *3)* God did this so that I might discover and make known his strength, for "His strength is made known through weakness." Now I must rely on God. *4)* I do not know why this happened, but I believe that "God works in a mysterious way his wonders to perform," and, although at this time I do not see how, I believe that "all things work together for good to those who love God." Somehow this is a blessing in disguise. *5)* God had nothing to do with it. He does not will suffering or imperfection. God has established laws. When we fully understand his laws (medicine and science are discovering more of them all the time) we will minimize, decrease, or eliminate suffering and handicaps.

The emotional reaction of an individual to accident, disease, or congenital handicap will depend in part on which of these attitudes he holds, and, since a patient's emotional reactions influence his response to therapy, it is important in considering the role of religion to recognize the diversity of beliefs even among the "devoutly religious."

Josephson[15] points out that the individual's religious beliefs will affect both the degree to which he participates in the rehabilitation program and the type of adjustment for which he strives. The client's reactions and choices will depend in part upon whether his belief or religious faith "sanctions acceptance of inferior social status, or whether it helps the person escape from that status and achieve some measure of social and economic independence." The farther a person is to the left of the dependence-independence continuum, and the more his religious beliefs sanction acceptance of an inferior socio-economic role, the less active and co-operative he will be in the rehabilitation processes and the easier will be his adjustment to *(i.e.,* acceptance of) a new role of dependency. (His handicap provides him with an acceptable or obvious justification for his dependency.) On the other hand, the farther a person is to the right of the dependence-independence continuum, and the more his religious beliefs help him maintain his sense of personal dignity and worth, the more he will tend to be active and co-operative in the rehabilitative process and the more he will strive for adjustment in terms of as near normal functioning as possible—even though the striving for that type of adjustment brings frustrations and disappointments and may not be achieved as quickly as the "adjustment" that means only acceptance of a dependent role.

The charge has been made that in America we "have religiousness without religion." Certainly it is true that many persons maintain an affiliation with or membership in a church, and even attend regularly, because it is socially acceptable behavior rather than because of any deep religious convictions. The recitation of a creed during church services is no proof that the creed and its implications for daily living are understood and accepted emotionally *(i.e.,* at the value-setting and action-determining level). The fact that some patients bring a Bible to the hospital and keep it open beside them is no indication that they are any more religious than those who do not. Indeed, Covalt[49] expresses the opinion that those who bring their Bibles with them are insecure individuals, frequently members of "small offshoot religious sects." She reports that these individuals are frequently unco-operative, fail to follow instructions, complain about minor details, and generally hinder their recovery. It would seem that a "desirable" religious faith would make a person more secure and stable, as well as more co-operative, and, if not more appreciative of the service rendered by the hospital staff, at least less critical of minor irritations.

One of the problems confronted by anyone who attempts research in this area will be to distinguish between the mere "professors" or "church-goers" and the "true-believers," that is, to determine which of the subjects have a profound faith as distinguished from those whose faith is superficial. Except as it indicates an area in which research is needed, to say that "religious persons" or "members of this denomination" are more co-operative than others in rehabilitation is misleading for the uncritical reader and meaningless for the critical reader unless there has been some measure of the depth and nature of the religious convictions of the persons involved. The same criticism may be made of statements to the effect that a handicap causes persons to become "more" or "less" religious. It is necessary to know the content and depth of the individual's faith both before and following the onset of the handicapping condition. To know that he was a Baptist or an Episcopalian, or that he "never missed a church service" is of some interest but leaves the basic question of the relation between his faith and adjustment, or other criterion, unanswered.

Not many studies have been published that deal with the differences in attitudes and concepts found in various religious groups. Those that were found suggest that there are significant differences. Knight made "A Study of Religious Beliefs and Attitudes of Senior Medical Students"[75] and reports significant differences in several areas. Sixty-seven students participated. They were graduates of church-related colleges (46%); state or municipal colleges (43%); and private, nonsectarian schools (11%). Methodists, Baptists, and Presbyterians composed 61% of the group; the remaining 39% included 7 Jewish, 4 Catholic, 3 agnostic, 3 Episcopalian, and 9 from other Protestant groups. Among the conclusions reached by Knight that may be pertinent to this study are:

1) Most of the Christians felt that there was no conflict between religion and science whereas the Jews were divided, with half feeling that there was no conflict and half feeling that there was.
2) Also, most of the Jews felt that the physician had no special role in relation to religion, whereas most of the Christians felt that the physician had a special role.
3) Baptists and Catholics unanimously felt that their religious faith would play an important part in their own lives as practicing physicians, whereas only half of the Methodists and Presbyterians felt this. Conversely, a large majority of Methodists and Presbyterians felt that the faith of their patients would be a positive force in healing and recovery from physical and emotional illness, whereas only half of the Baptists and Catholics felt that way. Thus, the patient's faith seemed more important to the Methodists and Presbyterians, whereas the Baptists and Catholics tended to feel that their own faith was more important.
4) Many felt that the physician should treat the whole patient and therefore should know about his religion. An equal number felt that the physician and the clergyman should work closely together. . . . In all, 75 per cent felt that the physician had a special religious role, though they differed as to the specific nature and extent of the role.
5) Most of the students recognized the importance of a patient's religion in relation to health and disease. The majority felt that a patient's faith is a positive force in healing and recovering from both physical and emotional illnesses.
6) Eighty per cent of the group felt that members of certain religious groups are especially prone to develop mental disorders. Many felt that certain groups attract persons who are already disturbed and that some mental disorder is a reason for group membership. . . . Others felt that certain strict religious groups seemed more prone to develop mental disorders. . . . Strict religious groups

tended to make demands in everyday life and limit the flexibility of their followers in adapting to new surroundings and situations, thus rendering them less able to achieve good mental health.

Cumming and Henry[50] report that a study of 211 persons 50 years of age and older indicated that Catholics and most fundamentalists received higher "Religious Piety" scores than did members of nonliturgical and non-evangelical Protestant denominations. It should be noted that "high scores" were earned on the scale used in this study by those whose religious beliefs are concerned with man's relationship to God, redemption from sin, and life after death; those whose religious beliefs are primarily concerned with the brotherhood of man, a philosophy of life, and social interaction received low scores. However, the meaning of the scores is of less concern at this moment than is the fact that denominational differences were found. Furthermore, although the majority of the persons in this study stated that religion had been of the greatest value to them in time of crisis, differences were discovered between the attitudes of members of different religious groups.

Boles[36] in a study of the parents of cerebral palsied children concluded that Protestant mothers were significantly less anxious than Catholic and Jewish mothers, and that Catholic mothers had more guilt feelings than either Jewish or Protestant mothers.

Zuk[123] in a study involving parents of retarded children concluded that Catholic mothers were more accepting than non-Catholic mothers.

With these indications of denominational differences in religious attitudes, it is obvious that, until much more research is done, any discussion of the "role of religion" must deal in generalizations—to all of which there will be more or fewer exceptions.

Although, as has been suggested, there are problems of measurement and evaluation, it may be both interesting and beneficial to attempt research that would provide answers to such questions as: Do members of some religious groups make "better patients" than do members of other religious groups? Are some more accepting of the illness, accident, or handicapping condition? Are some more co-operative during therapy and treatment? Are some more determined to achieve independence? Do some maintain or achieve a happier outlook on life? If "denominational" differences exist, what are the determinant factors (*i.e.*, What concepts, teachings, or procedures produce the differences)? How may a knowledge of these differences be used to improve rehabilitation procedures?

The Role of Religion

Does religion have a role in the rehabilitation process? What is its role? What does or what can religion contribute?

From the 31 correspondents, two "negative" replies were received. Covalt[5] stated, "I do not believe that you will find any association between religion and rehabilitation. The many hundreds of patients that I have seen since 1946 would certainly bear this out, for surely in that time if religion had a special meaning I would have met it, and I never have." Dr. Covalt has specialized in physical medicine and rehabilitation exclusively since 1946 and states that she has "yet to find the first patient who has discussed religion or made any mention of it after he has been disabled." She does not believe that becoming disabled causes a person to become religious. "All I know about their religion is that they complain to me occasionally of ministers with whom they are unacquainted and who represent another church denomination walking in to see them in the hospital."

The role of the clergy will be considered later, but it is interesting to note that Dr. Covalt is the only correspondent who commented unfavorably on the conduct or the contribution of ministers and chaplains in hospitals, schools, and rehabilitation centers.

The second negative comment came from Rabbi Nathaniel S. Share[23] who stated: "As I see it, religion has no direct contribution to offer to the rehabilitation process." He goes on, however, to point out *1)* that the motivation to help the handicapped comes from the "religious teaching of the infinite worth of the individual and of our common responsibility, one to the other," and *2)* that "the institutions of religion may play an active part in rehabilitation work" in terms of nursery schools and religious classes for the mentally retarded and other such projects. He stated that what he has done for the mentally retarded he did "as a person, as a parent, as a citizen and not as a rabbi, although I would be the last to deny that the teachings of Judaism were a basic motivating factor."

Twenty-nine of the 31 correspondents expressed the belief that religion has a part to play. Two thought that religion has "no special message" for the disabled but offers the same spiritual resources to all men. Several stated that religion plays "an important part in rehabilitation," although they found it difficult to be specific. Others wrote several pages enumerating specific ways in which religion (and churches) function in relation to rehabilitation. Unfortunately, space does not permit the quotation in full of all of the letters received. Indeed, so varied were the responses that it is difficult to group them for summarizing, or even to quote from them without losing something of the emphasis, if not the intent, of the writer. Admitting the existence of this danger, it may still be useful to consider the opinions expressed as they relate to: *1)* religion as a motivating force, *2)* religion and the therapist, *3)* religion and the client, *4)* the role of the clergy, and *5)* the role of the church.

Religion as a Motivating Force

Although a few authors dispute the claim (it would be interesting to know something of their personal religious background), it is generally agreed that the religious teachings of Judaism and Christianity concerning the rights and worth of the individual are the primary motivation for our rehabilitation programs.[23, 98, 106, 119] Although the economic argument that it costs less to rehabilitate than to provide custodial care is undoubtedly a factor in the thinking of some, the majority of writers seem to believe that the religious teachings of "the good neighbor," the Golden Rule, "love thy neighbor as thyself," "a cup of cold water given in My name," and "Inasmuch as ye have done it unto one of the least of these" have served as the motivating force in the creation of our rehabilitation services.

Schoenbohm[73] believes that—

> Our desire to help the handicapped must result from the conviction that it is the Christian and democratic thing to do—from the belief that all men are brothers and that in the sight of God all are equal—that all of us live by the grace, mercy and forgiveness of God. . . . The Christian church has a double ministry—that of preaching and healing—and without the latter, the former has little effect. Faith without work is dead! If our Christianity means anything, it means that we must be interested in suffering humanity. . . . For this concern for the welfare of the individual, particularly the handicapped individual, was the pattern of Christ's life.

Furthermore, the religious motivation "to serve one's fellow man" has been an important factor in the vocational choice of many who have entered medicine, nursing, and the wide variety of services that play a part in the rehabilitation process. Some denominations include many of the professions involved in rehabilitation along with the ministry and directors of religious education in what they term "Christian service."

Granted that there would be many unconscious motives, it would be interesting to see the results of a comprehensive survey of the reasons given for entering the various professions related to rehabilitation and to study the possible relationship between vocational choices and specific religious concepts or experiences.

Religion and the Therapist

Knight's study[75] revealed that 60 percent of the senior medical students questioned had a strong personal commitment to a religious faith and expressed the belief that their religious faith would be an important factor in their life as physicians.

Both Brooks[37] and Deane[6] in writing of the rehabilitation of the mentally ill emphasize the importance of commitment, optimism, and compassion and suggest that these "essentials in the atmosphere" are the same as the religious concepts of "faith, hope, and love." Brooks also observes that large numbers of the personnel in mental hospitals stayed on the staff not because of financial reward but because of their compassion for the patients.

Brooks, Deane, and Ansbacher,[40] reporting on the Vermont Project for the Rehabilitation of Chronic Schizophrenic Patients, state that one of their "most important findings" is that anyone who "is of good will may be therapeutically effective."

It may be noted that when Jesus spoke of "loving our neighbors" he used the word *agape*, which refers to "invincible good will"—that is, good will that is bestowed not on the basis of merit but because of concern for others.*

Is there a relationship between *a)* the religious concept of love as "invincible good will," *b)* the conclusion that anyone "of good will may be therapeutically effective," and *c)* Thompson's[25] belief that "a broad religious background seems to produce a somewhat better result in counseling"? In discussing the relationship between "a broad religious background" and successful counseling, Thompson states: "This may be because many of our problems are rooted in religion. On the other hand, a religious person may have a more sympathetic understanding for people."

Although there is no objective data to support the hypothesis, my own observations, which deal primarily with teachers of mentally retarded children and therapists for speech and hearing problems, suggest that, of therapists with essentially comparable professional preparation, those with a wholesome religious background produce better results than do those who do not have such a background.

Related to this line of thought is Oeschger's[20] premise that " 'a cup of cold water given in His Name' is better and more therapeutic for the needs of people who hurt, than just a cup of cold water."

West[118] believes that—

> what a therapist thinks he is doing and what he actually does may be two quite different things; . . . the theoretical rationale for his therapy and the actual therapeutic principle at work may not coincide. . . . but the implication is that in cases in which stuttering therapy is effective, the patient has such faith in the therapist that, no matter what the therapist does, the patient will receive some benefit. We come then to . . . the faith-inspiring qualities of the therapist. These are, of course, quite varied: his professional reputation, the certificates on his office wall, the attitude of the patients in his waiting room, etc., but above all, that subtle, difficult-to-define thing called personal magnetism. This is a complex of impressions made upon the patient. The therapist possessed of this ability to impress the patient seems to be frank but tactful; penetrating but understanding; professional but kind; confident but humble.

It would be interesting to know if a religious faith contributes to the development of these characteristics and

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*Laymon, Charles M. *The Teachings of Jesus for Evangelism.* Nashville, Tenn.: Methodist Publ. House, 1961. p. 42.

whether there are specific religious teachings or concepts that are significant.

Felton[13] states: Although "it is conceivable that those who come from cultures wherein the interstices of life have been filled with strong devotional behavior can bring about a better form of rehabilitation," it is his opinion that "an agnostic can head up a program just as well," provided "he is tolerant and understanding of some of the methods of meeting the needs of the clients" and understands the "theoretical worth of this modality (religion) in the total program being offered."

Josephson[15] does not believe that the therapy administered by a religious person is necessarily better or more effective than therapy rendered by a nonreligious person. He suggests that "to find out one would have to compare the records of therapists who are agnostics with the records of those who are deeply religious." In the light of the studies by Knight,[75] Boles,[36] and Zuk,[123] it would seem to be necessary not only to distinguish between those therapists, doctors, and nurses who are agnostic and those who are deeply religious, but also to distinguish between members of different sects or denominations; furthermore, and probably most difficult, such a study must distinguish between "wholesome" religious experience *(i.e.,* experience or beliefs that have contributed to "good adjustment") and "unwholesome" religious experience *(i.e.,* experience or beliefs that have contributed to conflict and "poor adjustment").

Knight's finding that 80 percent of his students believed that "members of certain religious groups are especially prone to develop mental illness" and Covalt's[49] observation that insecure, unco-operative patients frequently belonged to "small offshoot religious sects" emphasize the importance of distinguishing between types of religious experience in any study of a possible relationship between religious faith and skill or success in the various fields of rehabilitation.

Summary

Rehabilitation has been defined and consideration has been given to the diversity of religious beliefs, both inter- and intradenominational, as well as to the differences in depth of conviction on the part of the individual. It is believed that both the depth of conviction and the nature of the religious beliefs of an individual are factors in determining not only the degree to which, as a patient, he will participate in rehabilitation but the type of adjustment for which he will strive. The role of religion as a motivating factor for the providing of rehabilitation services was discussed, and a question was raised concerning a relationship between the religious experience of a person and his effectiveness as a therapist.

In Part II consideration will be given to religion and the client, the role of the clergy, and the wide variety of services provided by churches. In conclusion, there are suggested a number of areas in which research is needed.

Part II

Introduction

Part I of this article, which appeared in the preceding issue of this journal, began with the making of two observations: *1)* The number of recently published books, study guides, and articles in religious journals is evidence of the concern of churches for the exceptional person. *2)* There is the possibility, as suggested by some writers, that—possibly because of the trend toward specialization in increasingly narrower areas, and in spite of our emphasis upon the "team approach"—our present rehabilitation programs do not recognize and seek to meet the needs of the "whole man."

From this background there arise such questions as: Does religion have a role in the rehabilitation process? What can religion contribute?

Rehabilitation was defined as including not only the restoration, but the conservation and cultivation of human resources. Religion was not defined, but emphasis was given to the importance (in any consideration of the role of religion) of the wide diversity of religious beliefs and the differences in depth of conviction. That is, in any research dealing with the relationship between religion and rehabilitation, it is necessary to determine *what* the client believes and the *depth* of his convictions, for these factors are important in determining the degree to which the rehabilitee will participate in the program and the kind of adjustment for which he will strive.

The role of religion as a motivating force for the providing of rehabilitation services was discussed, and a question was raised concerning the relationship between the effectiveness of the therapist and the nature of his religious experience and convictions.

Religion and the Client

The views of the correspondents concerning religion and the client were quite varied, as is shown in these three brief quotations; "If they have not been ardent church-goers before their disability, they do not become religious."[5] "Most of the principles of Christianity apply equally to both the able and the disabled. I have never felt that Christianity had any special message for me just because I am blind."[2] "To many religion becomes meaningful only when they are met with a crisis . . . and find their strengths unequal to the task of coping with the problem it presents. At such times they join with others, who have always found satisfaction in the spiritual aspects of life, and turn to religion for the comfort and hope they need to go on living."[14]

"Do disabled persons become religious—or more religious?" is not the question being raised. Nor is it, "Does religion have a special message for the disabled?" Indeed, Lentz[80] states that "handicapped persons do not need a different kind of religious faith. They may be forced to rely more heavily upon their religion than others," and "A sense of grateful stewardship is not inconsistent with handicaps."

The question pertinent at this point is, "Does religion have something to offer the rehabilitee?"

As was stated in Part I, most of the medical students in Knight's[75] study believed that a patient's religious faith was an important factor in recovery from illness even if the illness "were organic in its basic nature."

Fosdick[56] wrote: "One way or another, it is true with all of us that the ultimate test of character comes when trouble comes. Then the question is not so much whether we will do a right deed as whether we can stand up with integrity of soul under what life does to us. . . . I have seen many magnificent comebacks . . . but I never saw one that did not involve a recovery of faith in God."

Probably no informed person would claim that all handicapped persons become more religious or "turn to" religion. But some, according to their own statements, do. It would seem unwise to discount their statements on the basis of preconceived notions or personal prejudice, or, for that matter, because one's own religious experience did not seem to warrant such a conclusion. A postpoliomyelitic patient in her midtwenties said—

> I went to church, and I prayed—but it was pretty superficial. Then I got polio. Maybe it's because I had time to think. Maybe it's because I suddenly grew up. Anyhow, I began to take seriously the promises of God. I claimed them, and He kept them. I'm ashamed to say that I had treated my religion like a spare tire. I didn't pay too much attention to it as long as I got along all right without it. But when the blow-out happened—I'm glad that I had that spare tire, and knew how to open the trunk to get to it. (Personal communication, quoted by permission.)

Dr. Centerwall,[45] wife of a pediatrician, wrote from personal experience:

> I also believed in God. I believed in him; but I did not rely on him. Relying on myself had seemed sufficient. I thanked God that he had endowed me with ability to make my own way so successfully. I was truly glad that God seemed to be going with me through life; but I didn't give much thought to whether I was going with him.
>
> Suddenly, for the first time, I was faced with a problem over which I had no control. . . . Even though my husband and I were doctors we had no skill that could change her (our child's) destiny.
>
> For once, as there was nothing I could do for myself, I had time to think and to listen to God. . . .
>
> When we come to him in faith, admitting our need, then we are truly with God and he with us."

Graybill[61] tells of being "completely helpless," but after several "years of rebellion" during which he was an "insufferably superior" but "blissfully unhappy" atheist, he started as "an experiment" to test "God's promises." He traces the development of his faith in God and reports both physical and emotional improvement.

Some disabled persons tell of dramatic and abrupt changes in attitudes as a result of a "religious experience"; others describe their long search, stubborn resistance, and gradual change.

Most readers will recall one or more disabled persons who, from their beds or wheel chairs, dispensed courage, faith, hope, and wisdom to those who came to them in need. They will recall also disabled persons who were bitter and unhappy. Here, then, is another area for study: Is religious faith a factor in determining which disabled persons become more gracious and generous and which become more selfish and demanding? How important is religion in determining the client's reaction to a disability? What are the factors that determine whether the person will become "more" or "less" religious after being disabled? Possibly some of the factors would be revealed in the answers to such questions as: Prior to the disabling, was his religious faith "deep" or "superficial"? Was his faith mature and reasoned or immature and unrealistic?

It is relevant to note the warning of Felton[11] that there are "dangers in enforcing too much religious activity upon the rehabilitee, for he is under the stress of acquiring new knowledge and of undergoing considerable re-education. To make mandatory a new way of life philosophically and spiritually might call for reserves which he does not have, and this would represent an error of as great a dimension as omitting spiritual assistance during rehabilitation." It would seem, then, that both the religious concepts or faith of the person before the onset of the handicapping condition and the manner in which religious counseling is conducted after the onset must be considered. Among the questions for which answers are needed are: Following the disabling, who counseled with him? What religious concepts were presented? How tactfully or appropriately? By whom? What religious interpretation of the disability was given?

DiMichael,[131] in discussing the intense feelings of hostility toward physicians and clergymen that some disabled persons experience, suggests that the cause of these feelings lies in their immature belief in the "wonders of medicine" or the "comforts of religion in adversity." He suggests that "in the middle of this open or disguised hostility is the question of God, pain, suffering, disability, and perhaps all apparent evil." Each disabled person must find the answer, not as "a scholarly exercise," but in terms of problems with family, doctor, therapist, friends, and clergyman.

Our question may be re-stated: Whether or not the disabled person utilizes it, what has religion to offer?

The following statement was issued from a conference in which delegates from 39 denominations and representatives from major national health and welfare organizations participated:

> Assured of God's forgiveness and with new strength to live in an unjust world, this client or patient can find a new freedom even from the tyranny of himself. He is able to withstand the ailments and the defeats which may drive man to despair because he has been helped to accept his dependence upon God and to find salvation in Him.[95, p. 24.]

Young[30] believes that "religion plays a very vital part in the rehabilitation process of any patient, whether in a general hospital or a mental hospital."

Roberts[21] writes: "We must bring the deepest insights of the Christian faith into the thought and experience of these persons so that they may be guided and strengthened through these spiritual resources."

It may be appropriate at this time to note that much of the writings of the existentialists has a "religious flavor" McLeish[86] states that existentialism has some of its roots in theology; in his opinion the "final outcome of existentialist therapy is not 'a satisfactory adjustment' in the ordinary sense of these words. Rather, it is a *commitment* by the patient to the notion of himself as a responsible, self-aware human being. This involves a decisive orientation to life."

Dyer[53] expresses much the same idea:

> From the point of view of existential therapy, a patient is "rehabilitated," not when he learns to work and behave like normal people, but when he becomes oriented toward the fulfillment of his own existence.
>
> The aim of existential therapy is to help the patient to experience his existence as real, as meaningful.
>
> To use existential therapy is to help the patient to come out of his shell, to help him to emerge from his past and present habits—to get out of his present adjustment, so that he can move on toward becoming his fully developed self.

Some of Deane's comments[6] seem to reflect the influence of existentialism:

> I think that religion does play an important part in the rehabilitation process, if we mean by religion a series of ideas having emotional meaning and which are outside the realm of science. What I mean is this, that a good many of our patients seem to undergo in either gradual or sudden ways an experience roughly comparable to what is referred to in religious thought as conversion. . . . In short, I think I see a place for what might be called "secular evangelism," in which all the emotional techniques associated with the old-fashioned revival would be utilized but with no reference to God or theological concepts being made. Rather, the idea would be to try to swing the patient's thinking and feeling to the place where he would be impelled to move and to change. This is much like saying he would be brought under the

> "conviction of sin." . . . This is not precisely dealing with sin in the religious sense, but it is the attempt to telescope a host of affective reactions into an experience requiring a decision and a sense of commitment to one's inner core of wellness and an abandonment of psychotic traits. . . . I think it would be correct to say that some of the rehabilitation process represents the New Testament at work. . . .

Several correspondents suggested that a person's religious faith could serve as a motivating, unifying force to enable him to call forth all of his inner resources and to utilize the help being offered him. Weiss[28] put it this way: "Religion can contribute to the rehabilitation process by serving as a *catalyst* to elicit the very best in a disabled individual."

Sheets[24] comments on the unique contribution of religion as follows:

> I see religion and religious faith as being a paralleling force to medical science and psychology rather than a potential competitive element. . . . In my experience, science per se does not propose to provide the individual with other than factual data. Therefore, I am not aware that the handicapped individual can rely totally upon scientific endeavor for personal reassurance. . . . Then it seems to be logical that for internal emotional stability and peace of mind the one stable answer to be sought is a practical religious faith. . . . I can see religion playing a very practical and a very beneficial role in giving substance to the basis for life and in giving hope for a life beyond this, and even establishing a rationale for suffering and hardship on the part of mankind. When meaning is given to life, there appears to be a paralleling tendency for the person to see his handicap in a more realistic perspective than might otherwise be the case. I can also see where this particular attitude might lead to a rising above the handicap rather than magnifying it or using it as an excuse for nonproductivity.

McCracken[84] in discussing "How To Handle Our Handicaps" states that self-acceptance is necessary—

> But there is a self-acceptance that is altogether too supine and indolent. Few things are sadder than to see men and women losing heart and hope, drifting into apathy and inertia, deliberately sentencing themselves to low levels of achievement. . . . There is no dishonor in having only one talent whereas others have five or ten. The dishonor lies in neglecting and failing to turn to full account whatever the gift that has been entrusted to our care.

Religion, then, serves as a motivation for and a challenge to the handicapped individual to use his abilities.

Eddy[10] writes from his experience as the superintendent of a state residential center for 92 educable children with orthopedic and neurological handicaps so severe that they cannot attend school in the community:

> "A sense of spiritual values is the need and the right of every child. . . . The exceptional child, in particular, needs the moral strength imparted by an understanding of spiritual values as they apply to his daily existence, with the need to understand himself, the world about him, its influence upon his life and the effort required to cope with social and economic problems. . . . The religious program of the Hospital-School involves voluntary participation . . . in the Catholic, Jewish or Protestant program. We have three chaplains, who serve on a part-time basis and collectively represent the major faiths.

Thompson[25] suggests that the degree of help derived from religious faith in time of crisis is determined by the nature and quality of that faith.

> Self-actualizing faith is different from dogmatic faith. Dogmatic faith reflects fear and uncertainty rather than positive convictions. People seek refuge in dogmatic faith because they can hide behind their beliefs and feel safe. But this security may be gained at the cost of failure to grow. Reasoned faith is not easy to achieve. . . . We need values today which can stand the test of reality. Our values must be relevant to the kind of problems we face. These values, when properly chosen, will serve us in time of crisis, both personal and otherwise . . . but unreasoned faith is likely to be too emotionally charged to help us think realistically.
>
> Religion in rehabilitation calls for reasoned faith. We attain this not from acceptance of dogmatic teachings, but rather through self-understanding. . . . Our love for God and dependence upon Him may be hampered by emotions which, misunderstood and poorly directed, can keep the individual from acting worthy of one made in His image. Religion can help us reach our highest selves regardless of whatever impairment may be imposed upon us.

Carlsen[3] writes from a background of personal handicap and as superintendent of a school for crippled children:

> Overcoming a physical disability requires drive, an intense desire to achieve, and the conviction that life holds something of value for you, whether handicapped or not. Since many disabilities cannot be removed even through the best rehabilitation methods, the individual must learn to live as fully and effectively as possible with a handicap. This may mean periods of frustration, discouragement, and even depression. So that he will not succumb to these periods but will come out fighting, he needs faith—faith in himself, faith in his fellowman, and faith in his God. This religion can help give him.

Although he has made no formal studies in this specific area, Knight [17] states that his—

> clinical observation is that religion can play a very important role in rehabilitation. The people who are being rehabilitated have often undergone and continue to undergo a great deal of suffering. A religious orientation often enables one to see and discover meaning in his suffering. This not infrequently releases certain creative factors in the individual which enable him to turn a negative and defeating situation into a positive experience. Also, despair and hopelessness often move into the path of people who have sustained crippling of one kind or another. The religious orientation is often an effective antidote against this, as well as against the meaninglessness of life when our strength is being sapped by either physical or emotional difficulties. . . . Religion with its capacity to relate an individual to his fellowman and to a Higher Power neutralizes this feeling of aloneness and isolation and brings one into the warmth of the human community.

Whitehouse[29] believes that "religion, by assuming that it has a better answer to unanswerable questions, can offer much comfort to those who say, 'What did I do to deserve this?' . . . Like all therapies, it should not be a dependent retreat and perhaps only a temporary crutch, but, for many, a constant and dependable source of comfort and courage."

Felton[11] believes that a strong religious conviction is a significant source of extra strength. This opinion was reached after extensive experience with Goodwill Industries and with the employment problems of several minority groups. Felton states that, without a strong religious conviction "on the part of the rehabilitee, the efforts expended in his behalf might not come to fruition," for, "without a basic faith to cling to during the periods of stress, there is little left which can provide support, encouragement, or any glimmer of possible hope."

In the opinion of Ferree[12] "religion can and does contribute a great deal toward the motivation of the individual to adjust to his particular physical limitation." Religion contributes to the rehabilitation of a person insofar as it helps him to reject the passive "acceptance of his fate as a punishment for sin or a burden placed on him by an impersonal God," and assists him to accept the belief that "God helps those who help themselves." Religion may also contribute to the adjustment of an individual by cultivating a belief in "the inherent goodness of man and his innate desire to be helpful to those afflicted," not on a basis of pity, but because of compassion and a recognition of his individual worth.

Although both the able and disabled need "religion and its benefits," Lee[19] believes that—

> The handicapped probably need and can benefit more from religious motivation and inspiration than most nonhandicapped persons, for the handicapped tend so often to suffer loss of self-esteem, of confidence and of acceptance. . . . Healing for the ill and the handicapped is divine. . . . Hope is an essence of religion. People live by it—everyone does. But *hope* is a far bigger word, a far more meaningful one for the handicapped, for they too often have too little hope. That's why the handicapped, especially, need the contributions that only religion can provide. Medical treatment, education and rehabilitation are the means society can provide to help *hope* become real.

In an address before the National Rehabilitation Association, Trevethan[132] said—

> We respectfully suggest there is no physical or mental rehabilitation complete without our recognition and appropriation of the resources which are resident in the religious heritage or faith of one's own choice. . . . We are in the business of rehabilitating—that is, recreating—men and women in their God given right to all the normal aspirations, responsibilities and acceptances which a freedom loving society bestows upon its members. Our task is always the responsibility of seeing beyond broken limbs, disabled bodies and mentally ill individuals to that bit of the divine we call human personality—the soul of a man or woman.

Trevethan quoted 19 statements made by workers in the field of rehabilitation and recipients of rehabilitative services; included were the following:

> "Religion helps to place in correct focus the self-picture the client holds. It helps them to see themselves as they really are—needs, strengths, weaknesses and all. . . ." "A religious faith can accomplish wonders in removing a feeling of inferiority or a sense of guilt and other emotional disorders which are frequently associated with physical and mental handicaps. . . ." "A religious faith is essential to motivation. . . ." "Religion does not promise us that we will have no trouble. It does give us strength to withstand difficulties and achieve a victory over our handicap. . . ." "Religion simply stated is to furnish a reason for living. . . ." "The basic role of religion is to inculcate in the individual a faith in a power greater than himself, which power, when communicated to the individual, releases hitherto untapped energies within himself."

Trevethan continued:

> One cannot read these statements without realizing deeply that perhaps religion is the one great factor in rehabilitation to which we have not given a full measure of attention or support. . . . I would go so far as to say it is not "a principal" but "the principal" factor in restoration to as near normal living as it is possible for the individual to achieve.

Earlier in this section there was presented some "testimony" from disabled persons concerning the helpfulness of religion. On the other side of the ledger are statements such as that of Kriegel that make no mention of religion. Kriegel[76] writes feelingly of the *hate* that motivated him in his determined efforts at rehabilitation. His statement "My body had forged a soul" is followed by: "At the beginning of this memoir I wrote that existence itself remains a puzzle to me. Why I survived, I do not claim to know. But I did. All I can do is to salute my body. For it was the body that chose. And the body chose well."

There is no intention to minimize Kriegel's achievement nor to question the accuracy and honesty of his report; however, it must be noted that this is a remarkable account! Not only is there no mention of religion, there is no reference to help of any kind—not even an encouraging word. Not every disabled person is left so completely alone. Some do receive help and encouragement, and some state that they found comfort, courage, and strength in religion. There is no obvious reason to question the honesty or accuracy of their reports.

Kriegel states that some of the manuscripts considered for inclusion in the book *Experiments in Survival*[76] were rejected because they were "blandly optimistic," denied their loneliness, and described their experiences with a handicap in a way that reflected "certain public conceptions" rather than their true feelings. Is it possible that some honestly written manuscripts were rejected because they did not meet Kriegel's personal conceptions? Could the presence or absence of a religious faith, or significant differences in religious concepts, account for differences in reaction to handicaps?

Knight[17] believes that for the disabled person "religion can be the bridge that ties him again in solidarity with the human community and neutralizes or minimizes a penetrating type of loneliness and aloneness which faces us in illness and during recovery."

Weiss,[28] writing as the Associate Director of the Amputee Psychology Project, Research Division, New York University, is even more emphatic. (It is interesting, if not surprising, to observe that the most forthright and positive statements came—not from the clergy, as might be anticipated—but from those involved in rehabilitation programs.) Weiss, on the basis of his observations, concluded that "religion is thus the most powerful catalyst. It can mitigate and even nullify excruciating pain, convert chaotic despair into spiritual meaning, endow the rehabilitant with a sense of divine purpose, and convert a passive helpless 'cripple' into a proud human being once again."

While Kriegel's statements have the authenticity of a person who writes from personal experience, the statements of others cannot be ignored. Difficult as it may be, research in this area is needed.

The Role of the Clergy

In his presidential address to the American Catholic Psychological Association, DiMichael[131] expressed the opinion that scientific psychology and religion should reinforce each other in making "a full life for man" and invited religious counselors, ministers, psychiatrists, and others to study this "area of deep human experience" so as to increase both the scope and the depth of knowledge in this field.

DiMichael suggests that there are frequently four "stages" of adjusting to a disability: regression, accommodation, adjustment, and, in the highest stage, integration (in which the disability is incorporated as a part of the patient's panorama but is no longer the focus of his life). In this process of attaining "total rehabilitation," DiMichael believes that the clergyman can play an important part.

The role of the clergyman in rehabilitation is outlined by Trevethan[132] in five areas: *1)* After the family and the doctor, the minister is likely to be the first person to learn of the disabling condition. As friend and counselor, he plays an important role in helping members of the family not only by bringing comfort and strength, but by helping them to see what must be done. *2)* The minister should know what agencies are available to render needed services and acquaint the family with these resources. *3)* He should prepare the congregation to understand and accept the handicapped person. *4)* He may acquaint the members of the congregation with the community's rehabilitation services and encourage their support. *5)* The minister may keep his congregation informed concerning the "modern miracles of rehabilitation" that are now possible and encourage them to help eliminate the prejudice that is often encountered by the handicapped.

In addition to elaborating on the role of the minister, and the church, in creating an atmosphere of understanding and acceptance, Palmer[98] describes steps that have been taken by ministers toward this goal. He outlines procedures that have been used in interdenominational surveys of community needs for special services and stresses the importance of the participation of ministers and their representatives in community planning.

Garrett,[14] affiliated with the U.S. Office of Vocational Rehabilitation, believes that "disabled persons often find in their contacts with clergymen the motivating factor which will enable them to make use of all of the resources available within themselves, their families and communities, to insure an effective and successful rehabilitation program." Evidence of the belief of the Office of Vocational Rehabilitation in the religious phase of the rehabilitation process includes: *1)* Support of a workshop to give guidance to a group of young ministers in working with the disabled and assisting them to become accepted citizens; *2)* support of a course to orient ministers to the problems of the deaf (other similar courses are in the planning stage, according to Garrett); *3)* support of an institute titled "Inter-Faith Conference on Religion in the Aging Process"; *4)* support of a training program now being conducted at Union Theological Seminary that has two objectives:

> *a)* To test the hypothesis that pastoral counseling in a rehabilitation setting has certain unique aspects that can deepen the insight of ministers into problems of disability and illness, that such insights can be taught in theological curricula, and that pastoral counseling can strengthen the rehabilitation team in its approach to the total patient; *b)* To make possible the development of teaching materials which might be used more broadly.

In the opinion of Krishef,[18]

> Clergymen and religious workers are moving toward a greater appreciation for and understanding of the role of the social scientist. Similarly and simultaneously, the medical and psychological professions now seem to be quite cognizant of the great importance that religion plays in the health and well-being of almost all individuals and their families. This converging of appreciation and understanding as well as knowledge about the other fellow's work has resulted in each—the religious leader and the behavioral scientist—being able to contribute far more than was ever possible before.

There is at present some confusion as to the extent of the roles of each profession. Krishef asks, "Just how far shall the clergy go in psycho-social counseling for the retarded and his family? On the other hand, how much of the spiritual can the psychologists or the medical practitioners bring into their work?" Each professional worker has his unique knowledge, resources, and skills, but there must soon be a delineation of "the specific functions and roles that each should provide in the helping process."

Krishef is convinced that—

> As the role of the minister becomes more crystalized, both religion and religious workers will be in a better position to provide even greater contributions in counseling the exceptional person and his family. The minister will be more adequately equipped to help the individual toward a deeper recognition of the value and importance as well as the meaning of his life. The clergyman, better than anyone else, can make a most significant contribution in stabilizing emotional and mental health of both the family members and the retardates themselves.

Krishef believes he should not attempt to become a "junior psychiatrist."

According to Krishef, the role of the minister includes helping parents to understand and accept their handicapped children, helping the handicapped through religious instruction and counseling that is geared to their needs, and helping the entire community become more understanding and accepting of the exceptional person.

Diller[7] states that from his experience with the physically handicapped it appears that churches and ministers can do a great deal toward rehabilitation. He believes that "ministers are often the only professional people who can maintain contact with some disabled persons." He refers to a recent master's thesis *(University of Southern California, Department of Occupational Therapy)*, which reports "a survey of the most severely involved disabled people—quadriplegics. This study demonstrates that once their active rehabilitation program is terminated a major source of growth is via religious experience."

Sheets[24] suggests six requirements for "a religionist who is going to be effective in this particular area."

> *1)* He must have a fairly keen understanding of the basic elements of human behavior. *2)* He must be accepting of people generally. *3)* He must be basically a secure and well adjusted person himself in order to meet, without undue emotions and identification, the problems of the handicapped person with whom he works. *4)* He must be accepting of handicapped persons and be able to see beyond their immediate physical and/or emotional deviations. *5)* His basic motivation for activity among handicapped people should be that of service and love of fellow man rather than self-aggrandizement in any form. *6)* The religious viewpoint brought to bear on handicapping conditions must be constructive, positive and uplifting rather than destructive and ego deflating.

Although one of the correspondents believed that clergymen in a hospital setting too often "get in the way of both doctors and patients,"[5] most correspondents pointed out the contribution that clergymen are making or may make. However, as Krishef stated, there must be a clarification of and a delineation between the roles of the various professions. Conferences between representatives of the professions involved should help, but more projects (such as the OVR project at Union Theological Seminary) are needed to determine whether counseling by clergymen has unique aspects of significance in the rehabilitation process. If they exist, how may these unique aspects be developed and strengthened? How may they best be utilized in the total program?

The Role of the Church

In this section attention is devoted to what various churches (*i.e.*, denominations and local congregations) are contributing or may contribute to the rehabilitation program.

The church has been criticized for becoming involved in various rehabilitation programs instead of "sticking to its business of saving souls," yet increasing attention to work for and with the exceptional person is found in church programs and church literature. Why?

During the past several years there has been a series of interdenominational conferences on the church and social welfare, sponsored by the Division of Christian Life and Work of the National Council of the Churches of Christ in the U.S.A. Out of these conferences have come statements that partially explain the interest of the church in rehabilitation:

> In order for the Church to be true to its role as the Body of Christ, it must manifest Christ's concern and compassionate action wherever there is human need.[95, p.8]
> The churches should recruit and train workers for a social ministry. This includes both full-time workers and volunteers. . . . Moreover, it should see that these workers are provided with Christian understanding and motivation and the best possible training and skill available for their areas of service.[95, p.10]
> In ministering to the whole man, it must express this relationship by working constructively with all those institutions and agencies which affect his welfare.[95, p.14]
> In response to the grace of God, the Church is impelled to awaken and maintain among its members awareness of, sensitivity to, and creativity in serving the whole man and all men as children of God.[95, p.28]

Among the objectives listed by the 1957 Conference on the Church and Social Welfare are the following:

> A. To produce a society in which every person has an opportunity to develop to the fullest capacity his God-given endowment and to make his maximum contribution to the whole community. . . . C. To help our members to assume their responsibility for programs of prevention and cure in the areas of health and welfare. . . . H. To promote the adoption of legislation designed to support health and welfare. . . . I. To promote among church members a sense of total involvement in community life and its problems.[95, p.30-31]

This statement of objectives is followed by a discussion of specific steps that churches and church members may take toward the attainment of these goals.

Many denominational and interdenominational journals have in recent years increasingly stressed the need for serving the handicapped and including them in the program of the church. The February, 1962, issue of the *International Journal of Religious Education* was devoted entirely to work with exceptional persons. The January, 1963, issue of *The Christian Home* has as its theme "The Church and the Home Minister to Special Needs."

In 1961 the National Council of the Churches of Christ published two books devoted to work with handicapped persons. *Who Cares?*, by Janette T. Harrington and Muriel S. Webb,[64] is a study of persons with exceptional needs and contains many suggestions for action to be taken by the church groups that use it as a part of their program. *The Church and the Exceptional Person*, by Palmer,[95] is one of the leadership training textbooks intended primarily for preparing church school workers to understand and serve the needs of handicapped persons.

Several denominations have prepared special lesson materials, particularly for the mentally retarded, and other denominations are now preparing such materials. The John Milton Society, interdenominationally sponsored, provides materials for the religious education of blind persons all over the world—both on talking book records and in braille. A curriculum, nondenominational in character, for the Christian education of the deaf is being prepared by the Protestant Episcopal Church. Local councils of churches and separate denominations sponsor religious education programs for persons in institutions. Theological seminaries and church-related colleges near institutions co-operate in these programs. The Evangelical and Reformed Church, in co-operation with the National Association for Retarded Children, is preparing a program for the Christian education of retarded children that is based on contemporary information concerning their potentials. The American Baptist Church conducted in 1960-1961 a "case-finding" project to determine the number, location, and classification of handicapped persons who need the ministry of the church and is currently evaluating the data in an effort to determine how best to meet the discovered needs. The Lutheran Church, with a long history of services to handicapped persons in institutions, has—in the light of new knowledge and insights—shifted its emphasis from custodial care to rehabilitative and training services. The Methodist-related Goodwill Industries began as a general relief and employment service for the needy but has developed a rehabilitative program that helps thousands of handicapped persons attain the fullest development possible. The National Benevolent Association of the Disciples of Christ has changed one of its orphans' homes into a home for children who are "mentally deficient and physically defective." The Presbyterian Church, U.S., opened a vocational school for mentally retarded youths in 1959. Baptist, Episcopal, Lutheran, Methodist, United Church of Christ, and other denominations have provided day-care and nonresident training for handicapped children. Many denominations operate a wide variety of institutions including hospitals and special schools. The Methodist Church alone has 244 institutions in the fields of health and welfare.

Church-sponsored projects include: Conducting courses to help leaders integrate persons with special needs into church groups; conducting courses to help prepare teachers to meet the problems of special classes for those with exceptionalities who need them; conducting special classes for the religious education of the mentally retarded, the emotionally disturbed, and the deaf; preparing, locally, special materials for the blind; recruiting and training volunteer workers to assist in hospitals, residential schools, and other institutions; working with alcoholics; working with drug addicts; employing ministers trained to counsel with persons of special needs; furnishing hospital chaplains. The American Hospital Association reports that 20.3 percent of 6,175 institutions have one or more full-time chaplains.

Various denominations conduct clinics, children's services, schools for the mentally retarded, schools for the emotionally disturbed, mental health clinics, homes, and recreational programs for the aging. They conduct centers that provide recreational and vocational training activities in an effort to prevent delinquency. They provide space for other agencies, leadership for co-operative mental health centers, homes for the chronically ill, and counseling services for all ages. They sponsor parent groups for counseling and therapy. They provide a variety of services for the home-bound. Nor does this exhaust the list!

In addition to these special services, several correspondents emphasized the importance of the fellowship and companionship that church activities provide. Krishef[18] believes an advantage of church school programs that include exceptional persons lies in the fact that they "not only can help these children from what they learn but can aid them to feel that they are a part of the church. These are children who are frequently rebuffed. These are children who must truly feel that they belong and are wanted if they are to be happy. This is a feeling that the retarded all too often have not been permitted to enjoy."

Oeschger[20] states that the demonstrations of the loving concern of members of a congregation reinforce and strengthen the handicapped person's belief in a God who loves and cares. He concludes: "In the 'after-care' phase of rehabilitation, religious experience becomes most important. If this resource has been effectually opened up for the patient, then it gives him a staying power for the times of slow-down and difficulty." He believes that "the modern counterpart of Jesus' healing ministry . . . is rehabilitation. When done properly, this church effort becomes part of the community rehabilitation team."

That more effort needs to be expended by churches in meeting the needs of exceptional persons and that many existing services should be improved can hardly be questioned. However, professional workers in the areas of rehabilitation should recognize the rapidly expanding programs provided by churches as evidence of their concern and their willingness to serve. The responsibility for the shortcomings that exist rests to a considerable degree upon the professionally prepared persons in various areas concerned with rehabilitation. Few ministers or church leaders have the professional preparation to enable them to envision what needs to be done or to determine the best way of doing it. "Specialists" are needed to serve as consultants in helping churches create programs of service or modify existing programs and facilities in order to better meet exceptional needs.

Efforts should be made to establish better working relationships between rehabilitation services and churches. Trevethan[132] made a survey of "a representative group of clergymen" and found that less than 5 percent of them had ever been asked to participate as a member of an evaluation or rehabilitation team, although all of them indicated a desire to be of service. It appears that full use of this resource is not being made by those primarily responsible for rehabilitation programs.

Areas for Research

Those who are concerned with the "conservation and restoration" of the whole man will find it difficult to ignore the opinions of so many persons prominent in the field of rehabilitation as to the importance of religion. There are, however, a number of questions to be answered. A partial list would include the following:

1) What are the proper lines of delineation between the roles of the religious counselor, the psychiatrist, the social worker, and the medical practitioner?
2) How can ministers be used most effectively on the rehabilitation team?
3) Does religious counseling, or counseling by clergymen, have unique aspects that are significant in rehabilitation?
4) How can professionally prepared persons be of the greatest assistance to church groups in planning services for exceptional persons?
5) How can what a man believes and how profoundly he believes it be determined?
6) Does a "wholesome religious background" produce a better therapist? Are there denominational differences? What specific religious concepts are factors?
7) Does a "wholesome religious background" make a better patient? Are there denominational differences? What specific religious concepts make a patient more co-operative? more accepting? more eager to be independent? more willing to be dependent?
8) Are there measures that churches, or ministers, could take to better prepare persons for facing disabling crises when they arise? Do other professions have responsibilities in this "program of preparation"?
9) What factors determine whether a disabled person becomes "more" or "less" religious?
10) Is the intensity or profundity of a man's belief more important for rehabilitation than what he believes?
11) If religious concepts are significant in rehabilitation, how may they best be utilized?
12) Is religion a factor in the motivation of those who enter rehabilitative professions? Are there denominational differences? What are the specific religious concepts involved?

Admittedly, it will not be easy to find answers to some of these questions. It is believed, however, that answers to such questions may serve two purposes: Furnish an explanation for some of the unexpected failures and successes in rehabilitation and make it possible to use more fully and effectively whatever resources religion may contribute.

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124. Carpenter, Rev. Jerry E. (Chaplain, Episcopal Hospital). Individual and Family Problems (Focus on the Individual).

125. Hatcher, Flora Y. (Assistant to the Administrator of Consumer and Community Group Relations, Housing and Home Finance Agency). Community Planning and Church Responsibility.

126. Klink, Rev. Thomas W. (Chaplain, The Menninger Foundation). Religious Needs of People in Institutions.

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128. Upjohn, D. Milo (Director, Family Counseling Service) Individual and Family Problems (Focus on Parents and Children).

129. Webb, Mrs. Robert W. (Associate Director, Dept. of Christian Social Relations, National Council, Protestant Episcopal Church). Services for the Mentally and Physically Handicapped.

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The Placement Process in the Rehabilitation of the Severely Handicapped

WILLIAM M. USDANE, Ph.D.

Summary

The rehabilitation service delivery system needs professionally educated and trained job placement workers as integral members of rehabilitation teams. Vocational program review and reevaluation mandated by the 1973 Rehabilitation Act demands highly qualified personnel to ensure employment for people with severe disabilities. Elevating placement in the hierarchy of rehabilitation services will transfer placement responsibility from heavily burdened rehabilitation counselors to specially trained counselors who can give clients labor market information and post-job adjustment assistance.

The continually expanding movement of people with disabilities into public and private business and recreation justifies the need for a specialist in affirmative action, agency-employer agreements, architectural barriers, economic fluctuation, and causes of unemployment. Placement workers within rehabilitation facilities will improve clients' employment opportunities.

THERE HAS BEEN as much discussion about the placement process as there has been about the weather, and with about the same accomplishment in effecting change or direction over the past 25 years. The placement process in the rehabilitation service delivery system has been professionally the least implemented area among the various services available from team members for the severely handicapped individual.

Professionalism in Placement: A New Frontier

The development of professionalism around such placement process aspects as job development, job solicitation, labor market forecasting for the handicapped, job engineering, job placement, and job follow-up has been excessively uneven. Despite continued focus on the employability of the severely handicapped in the Rehabilitation Act of 1973, as amended in 1974, professional development in the placement process as a distinguishable entity for graduate training has been minimal. As yet, for example, there is no distinct graduate program, either supported by the Rehabilitation Services Administration or otherwise, that provides training for a Placement Worker.[1] While there may be a course or two in the placement process, or a "track" emphasizing placement counseling as one of several "tracks" in some of the Rehabilitation Counselor graduate curricula, the major focus in these programs, as it should be, is on the counseling emphasis.

A new frontier needs to be developed within the rehabilitation service delivery system for the placement process. As Dunn states in his December, 1974, monograph on placement services: "Concern with placement and eventual job adjustment must be evident at all stages of the process, not merely confined to the end stage."[2] This monograph is another product from the Research and Training Center at the University of Wisconsin at Stout in Menomonie, focusing on vocational evaluation and work adjustment. Just as these two important areas have come of age

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through the direction and leadership of Stout, Alabama State University at Auburn, the ICD Research and Training Center in New York City, and others who have combined their early frontier-pushing in current professional organizational and journal activity, the placement process needs equal, aggressive professional leadership in innovative and experimental development. Such progress is especially important within a rehabilitation service delivery system that signifies employability as the capstone of the total process for the severely handicapped person—either immediately or on a long-range basis. Job development and job solicitation are slowly gaining professionalism but, as yet, without evidence of strong and acknowledged university support.

Dr. Andrew S. Adams, Commissioner of Rehabilitation Services within the Department of Health, Education, and Welfare, recently talked about employment of the handicapped and the importance of the placement process:

> I am just not satisfied with the efforts that are being made to get handicapped people employed. I am also concerned that after they are employed . . . they have maximum upward mobility on the job. . . . Unless our society can help handicapped people work at their maximum highest levels, . . . society won't get full return from the work of the handicapped.[3, p. 66]

A special report to Congress, mandated by the Rehabilitation Act of 1973, is *The Role of the Sheltered Workshops in the Rehabilitation of the Severely Handicapped.* Using a randomly selected sample of 400 workshops, the study projects that, in the total number of 2,766 Department of Labor-certified workshops, 410,000 are served annually, while 182,000 leave the workshop each year.[4] An estimated 10 percent of workshop clients from the total certified workshops in the country are placed each year in competitive employment. Of the 140,000 served daily by workshops, about 100,000 are engaged in long-term remunerative employment. Section 101 of the 1973 Rehabilitation Act notes that an annual plan for vocational rehabilitation services must provide for a periodic review and reevaluation of the status of these handicapped people placed in extended employment in facilities or workshops. The periodic review must determine the feasibility of employment or training for placement in the competitive labor market. That section plus the new written plan for individualized rehabilitation are primarily to insure the employability of the severely handicapped person. Professionalism in the placement process is needed now and in the future more than ever before.

Placement Reconceptualized

The placement process needs to be reconceptualized. Perhaps a simple starting point would be to start out merely with the current fixed list of services. Placement's position in the linear litany of rehabilitation services is sequentially always under *vocational* at the end of the line—medical, psychological, social, recreational, and vocational. Within the vocational area, again, the usual linear order is customarily counseling, evaluation, work adjustment, training, and, last and least, placement. The counseling relationship in an early interaction between the disabled person and the Rehabilitation Counselor is always a primary consideration. But rarely does that interaction always include, in its early primary focus, placement. While it might be somewhat simplistic to think that workers in the field of rehabilitation tend to consider the placement process only after the other services are accomplished, it is still apparent that there is yet no one trained as a professional Placement Worker to change that impression.

Placement responsibility within the state-federal program is mandated as another part of the Rehabilitation Counselor's functional role. In many rehabilitation facilities, the placement responsibility is often deferred until the State Rehabilitation Counselor arrives on an itinerant basis. Even if there is a Rehabilitation Counselor as a paid staff member of the facility team, emphasis is usually upon the counseling and assessment areas. Placement itself usually gets lost in a referral shuffle. It often becomes part of the "referral" process, or the client is "prepared" to get his own job. The counseling process itself can admirably prepare a disabled person for eventual placement, but that process may not always have behind it a professional discipline that would consider job development, job solicitation, and job engineering as major parts of the placement process. This article in no way claims that these last three components must be major or primary components of the curriculum involving the training of the Rehabilitation Counselor. Certification currently under way in Rehabilitation Counseling and accreditation of Rehabilitation Counseling graduate curricula have both made giant strides in their accomplishments.

Placement consideration, however, will not appear early in the rehabilitation process and persist throughout unless there is a discipline for this expressed goal that is given such specific responsibility as an equal member of the team. The so-called capstone of the rehabilitation process involves provision for labor market information as well as provision for post job adjustment assistance. The linear sequential conceptualization of services, however, puts the placement responsibility at the end of the service delivery line. The severely handicapped person is the one who loses. With the current expressed legal need to remove transportation and architectural barriers, the role of the Placement Worker becomes even more crucial as a necessary identifiable team member. The entire affirmative action program that is now a part of the rehabilitation consciousness through Title V of the Rehabilitation Act of 1973 can be best achieved through the expressed responsibility of a Placement Worker.

The rehabilitation team, however, rarely includes any person who has been *a)* professionally trained in the gamut of knowledge through graduate work centered around this process and *b)* given the specific responsibility early in the process for job development, job solicitation, economic job forecasting, labor market information, job engineering, job placement, and post job adjustment. Even innovative service programs involving career development for the severely disabled appear to dwell lightly on the insistence of individual placement assistance.[5] Since they are concerned with the development of skills for the severely handicapped as paraprofessionals in health-related fields, there is little highlighting of the actual placement process. Instead, the central theme of the project is career development, or the training aspects. But without the assistance of a professionally trained Placement Worker, such career training either may be a dead-end goal or will provide minimal satisfactions for the severely handicapped person from nonpaying volunteer work. Training and preparation for the expectation of an actual job, but without job achievement or realization, obviously will be harmful to either a disabled or a nondisabled person.

The George Washington University Medical Center conducted a conference on comprehensive vocational rehabilitation for severely disabled persons.[6] The material in the section on Job Development and the Placement Process made little if any reference to the development of a professional as a Placement Worker. Instead, empirical experience was reviewed. There was good evidence, nevertheless, that someone called the Placement Specialist or Placement Counselor utilized community resources for referral and often engaged in engineering a simulated job for occupational exploration. But the placement process was presented without any synthesis of principles, or without a suggestion of an appropriate training base. Although this was not the purpose of the conference, it was apparent that, on the team, evidence showed the need for someone who might be called a Placement Specialist or a Placement Counselor.

Again, it is timely to reconceptualize the steps of the rehabilitation service delivery system so the placement process may be given continued consideration *throughout* the linear order. The best of intentions by members of the team who are not placement-minded may end up shortchanging the rehabilitation capstone of the severely handicapped person.

It is recommended that any reconceptualization include placement as the pervasive underlying principle throughout the rehabilitation process. The counseling principle is, of course, important as the mode of interaction, but the major outcome—placement—is also the major expectation of the handicapped. This age is the age of the consumer, and the placement process of optimal achievement is an appropriate legal expectation of every handicapped person experiencing the State Vocational Rehabilitation program.

Even internationally, the order of service with regard to the placement process and the needs of the Placement Worker are noted in a Regional Seminar conducted in Poland and cosponsored by both the United Nations Development Programme and the International Labour Organization:

> The biggest problem facing rehabilitation teams comes at the end of courses when disabled trainees found to be suitable and prepared for specific jobs in commerce or industry seek employment opportunities. A qualified placement officer, a member of the team, has the responsibility of keeping in touch with . . . personnel departments, trade unions, . . . chambers of commerce, and individual employers in an effort to find suitable openings.[7]

The sequential deferment of the capstone process shows up in Public Law 93-112, Section 103 (a)(2), the Rehabilitation Act of 1973: "counseling, guidance, referral and placement services for handicapped individuals."

Professional and Functional Role of Rehabilitation Counselors

Throughout the graduate training programs, the model of professionalism before the Rehabilitation Counselor trainees is that of the educator or the professor. For the most part, the educator is essentially a psychologist or a guidance counselor, and clearly not a Placement Worker. The focus of any counselor training program is on the counseling process. Rehabilitation counseling, appropriately, emphasizes the counseling interaction, at times preparing the disabled person for placement. The functional role of the Rehabilitation Counselor within the State Vocational Rehabilitation Agency is that of case manager, counselor, and placement counselor. Case management and many internal managerial priorities occupy the daily activities of the State Rehabilitation Counselor. Time for the counselor model often is very limited. In the state agency the model for the Rehabilitation Counselor is far more that of a case manager and case coordinator, with focus on placement counseling. Dunn includes 21 administrative and program recommendations to State Vocational Rehabilitation Agencies that would improve placement of the disabled.[8] Number 17 states the case strongly: "Recognize the widespread negative attitudes of rehabilitation counselors toward engaging in placement activities and the futility of forcing them to do so."

Scorzelli in a recent article[9] noted that, despite previous research on Rehabilitation Counselor program content and present Rehabilitation Services Administration guidelines stressing the importance of job placement and follow-up services, his results suggested the contrary. The model supported for the role and function of the Rehabilitation Counselor was that of counselor-coordinator.[10] He also noted the low professional role of placement in the eyes of his small sample of 55 employed Rehabilitation Counselors. They felt that it "might be more efficient and practical to relinquish job placement and follow-up to support personnel and para-professionals."[11]

A 1972 conference[12] on role and functions of the Rehabilitation Counselor also noted that areas of job development and placement activities should be given to support personnel, "lesser trained and functioning in more of a specialized nature in the rehabilitation process." A five-year recent nationwide field study on the rehabilitation process as it relates to client outcome arrived at interesting results in relationship to Rehabilitation Counselors' work role and their interpersonal skill level. Interestingly enough, the study "was restricted to counselor interview behavior; thus activities the counselor performs for the client such as job finding and placement are omitted from consideration."[13] Once again, placement is omitted from any consideration in the study as a major focus or emphasis in Rehabilitation Counselors' performance outcomes. The study, in fact, suggests that greater consideration be given from a work rewards standpoint to counseling emphasis. Another major suggestion from the results of this study was to "consider psychological change *per se* as a possible rehabilitation goal."[14]

Placement techniques are often provided after graduation from graduate Rehabilitation Counselor programs through inservice or short-term training. These various types of training continue to be taught by people essentially trained as counselors. Staffing of such workshops usually includes a State Placement Specialist who has been successful in the field of job placement, who essentially was initially trained in Counseling, but whose functioning on his job is very different from the type of academic graduate training received.

The model of a Rehabilitation Counselor is that of a counselor and was never intended to be that of a Placement Worker. The Commission on Rehabilitation Counselor Certification has received over 5,000 applications from Rehabilitation Counselors requesting participation in the certification program. The outstanding professional advance of the Rehabilitation Counselor as a counselor is clearly evident in the certification process and the curriculum accreditation process. The role and function of a new profession, called the Placement Worker, in no way would deny the pivotal and important role of the Rehabilitation Counselor as the major professional throughout the rehabilitation process for the severely handicapped. Like the Work Evaluator, the Placement Worker would cover a distinct and necessary process.

Role and Function of the Placement Worker

The role and function of the Placement Worker involves primary focus upon the full placement process resulting in the eventual employability of the severely handicapped. All activities are clearly and intimately related to the placement process in order to provide representation on the rehabilitation team equal with the psychologist, physician, rehabilitation counselor, social worker, and others. Responsibilities include, as mentioned earlier and in addition to job development and solicitation, bridging affirmative action policies and agreements between employer and the rehabilitation agency. Included would also be the reduction of architectural and transportation job barriers. Also included must be knowledge of labor market information, knowledge of economic periods of job fluctuation, knowledge of business cycles of expansion and restraint, and causes of unemployment. The Placement Worker should be aware of labor-management relations, laws governing this relationship, management practices and procedures, union practices, and collective bargaining. Job engineering is a related important underpinning and has already been mentioned as part of the Placement Worker's knowledge.

It would never be denied that others, especially the Rehabilitation Counselor, are also involved in the placement process. Everyone on the rehabilitation team has claimed to have done any one of a variety of jobs, including placement. The effects, however, in many cases have been less than successful from the client's viewpoint.

There is, incidentally, far more spillover and reinforcement of job functions within a rehabilitation facility among the psychologist, social worker, and rehabilitation counselor than there would be between any of these professions and that of the Placement Worker.

Need for Placement Worker Model

As yet, there is no model provided either on the campus or within the public or private field of rehabilitation for a professional Placement Worker. Current roles undertaken on placement are those of the Placement Specialist or the Placement Counselor. Both these titles are essentially "remade" Rehabilitation Counselors through the new title and some inservice training. Nonprofessionals from many types of backgrounds and experience are found in rehabilitation facilities acting as placement persons. Volunteers are often asked to serve in this capacity.

Until one or more specific graduate training programs within Departments of Economics or Business Administration pilot a curriculum for a Placement Worker, there will continue to be a lack of any appropriate professional model.

The Referral Process: Contacts, Intervention, and Careers

It is at the point of placement within the rehabilitation service delivery system that team members tend to refer the disabled or severely handicapped person to another agency. The Employment Service is not included in this discussion since the point made here is that the complicated involvement of individualized job development and solicitation cannot assume to be handled through referral outside the agency primarily responsible for the rehabilitation process. Referral within the placement process is considered as referral to an actual job or the probability of a job. Within the placement process and from the expectation of the disabled, referral must be considered in relationship to an actual job, or to a job opportunity.

The complicated placement process in all of its extensive manifestations is described convincingly in Granovetter's study of contacts and careers.[15] He discusses referral networks that professional, technical, and management job seekers use to get where they want to be. The study concerns a group of job-changers with emphasis upon why some of them seemed to have the right contacts that others didn't. He implies in his study the need that professionally well-qualified, nondisabled candidates have for help in the placement process. Also implied for the rehabilitation field is the essential need for a well-trained placement worker who would provide strong contact advocacy and community intervention for the severely handicapped person. The study outlines how to track into the transmission of employer job information material concerning a vacancy to the proper individual who can ultimately fill the vacancy.

Having the right contact at the right time in the right place for the right job is assumed by the casual observer to be luck. But, quite to the contrary, Granovetter scientifically tracks the system by which the knowledgeable Placement Worker could provide proper job development and job solicitation for his client. He points out that blue-collar studies over the past 40 years have had similar outcomes to placement: The formal mechanics of job placement rarely represent more than 20 percent of placements. Instead, 60 to 90 percent of jobs were obtained informally and primarily through friends and relatives. Direct application was found to be better than the formal approach through the employment agency, either public or private.

Granovetter, for example, found that the "actual transmission of information about job opportunities becomes a more immediate condition of mobility than any characteristics of jobs themselves." According to him, too much of the substantial research and writing about the placement area has been created by American labor economists, "motivated primarily by concern with either unemployment or labor shortage."[16] His view is that the contacts necessary for getting a job, especially in the career level, is as much a consideration of the sociological dimension as the underlying economic theoretical framework concerned with labor markets and wages. Apparently these economic concepts are not to be discarded, but to them should be added the understanding that the better jobs are found by "word of mouth."

Many a seasoned placement specialist or placement counselor has found that the "little black book" of names, addresses, firms, contacts, relatives, and other social sources successfully placed handicapped people. But this sociological plus factor in the placement process needs professional undergirding with economic and theoretical frameworks concerned with labor markets. Yet, without the professional training in Placement Work, there will continue to be the [illegible] turnover within rehabilitation facilities of counselors who start their facility career with the responsibility of placement. As these people become more and more proficient with the "contact circle" and knowledgeable of job placement techniques, advancement within the placement area is minimal. As a result, management, supervision, or higher pay in regular counseling positions contain the person from continuing what has been a creditable performance and service to the handicapped. Another novice then repeats the placement learning process on the job, and the cycle continues.

Another book on job finding is by Richard K. Irish, *Go Hire Yourself An Employer*. The content is usually perceptive and considerably cynical about approaches to the job-finding process. Geared to the professions or highly technically trained individuals, the book refuses to take seriously either the State Employment Services or any private employment organization. Irish, in an amusing vein, follows the sociological approaches scientifically considered by Granovetter. "Avoid employment agencies like the plague," he cautions.[17] Both authors by obvious implication indicate that the severely disabled could well use the professional assistance of a Placement Worker as a regular member of the rehabilitation team.

Summary

The placement process in the rehabilitation services delivery system is considered far too late in order of importance for the severely handicapped. This may be due to the linear representation of the services provided, bringing in the placement process at the end of the sequence. Reconceptualizing, even simply, the particular area of the placement process by showing it as an undergirding principle, rather than as a discrete service at the end of the service delivery line, provides a pervasive impact throughout the various services. To reinforce the importance of this particular area of important service, there needs to be developed professionally a new professional, the Placement Worker. Training should be at the graduate level in a department of either economics or business administration.

Placement responsibility, while remaining that of the State Rehabilitation Counselor in the State Vocational Rehabilitation Agency, could be greatly enhanced through the development of a Placement Worker as a professional entity within the rehabilitation center or the sheltered workshop. It is within the rehabilitation facility that the major contribution of a Placement Worker could be not only clearly identified but given the responsibility necessary. With such a professional re-look at the entire placement process by the rehabilitation field, the severely handicapped person will have a far better employability future than is possible within the current service delivery system and the current professionally trained rehabilitation team members.

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Physical Rehabilitation and Family Dynamics

HILDA P. VERSLUYS, OTR

Summary

Rehabilitation failure, when there is no other observable reason, may be the result of disordered family dynamics, family alienation, or the collapse of a concerned but overwhelmed family. Even a stable family group may be disrupted by the stresses involved in caring for the disabled individual.

Family responses to a disabled or chronically ill member, including both adaptive and pathological responses, are examined. An overview of how families deal with the stress of having an ill or disabled family member is provided. Suggested are models of treatment and counseling guidelines that influence and actively involve family members.

THE ROLE OF THE FAMILY in rehabilitation is crucial. The family's response to the injured or ill person may determine the patient's motivation to tolerate painful procedures and long-term treatment, to face irrevocable losses, and to accept major lifestyle changes. The nuclear family is ill equipped as an organization to deal with stresses and tasks of a severely disabled member. Family size and age distribution of its members limit the role substitutions possible.[1]

Excellent treatment programs may never realize their potential due to the collapse of a concerned but overwhelmed family. One family solution to such a crisis may be alienation and withdrawal from a relationship with the patient. Even a stable family may be disrupted by a consideration of the stresses involved in caring for the disabled patient.[2] The treatment of choice should involve not only the patient in collaboration with the rehabilitation team, but the family members as well, in programming and individual consultations that meet their needs.

Family Reactions To Stress

The Role of The Family

An adequately organized family can meet the multiple emotional needs of its members and deal with the stresses and uncertainties of life. Such a family can resolve stress through interfamily action. For example, family members can: *1)* temporarily decrease their own personal ambitions to deal with family crisis, *2)* work out new role patterns to carry on family functions, and *3)* develop collective goals in time of emergency and work toward them cooperatively.[1]

These families usually have previous experience and success in mediating crisis; they have the ability to adapt to change, there is affection among the family members, a good marital adjustment, and a family history of meeting problems through interfamily discussion and problem solving.

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An inadequately organized family is vulnerable to crisis because family roles are inadequate to deal with stress, member behaviors tend to precipitate more problems, and the flexibility to reorganize or to role share in an emergency is lacking. Such families have difficulty in making consistent commitments and in supporting the patient. Their interactions with staff and the patient may impede or prevent rehabilitation success.[illegible]

Family responses can be positive and supportive; for example, family willingness to reestablish and maintain the patient's valued roles, the involvement of the patient in family decision making, and family understanding of the kind of support useful to the patient. The family responses can also be negative and pathological, leading to overprotection, encouragement of dependency, neglect, avoidance of future planning, denial of the diagnosis, excessive and inappropriate demands, and punitive action toward the patient.[1,4,5]

Patients do not make accommodations to physical illness or disability independently of their families. Even intrapsychic processes such as the movement from denial into mourning or the renegotiation of early fears (such as the fear of abandonment or destruction of self) may be influenced by family attitudes or values. Influencing factors may include family attitudes of rejection or hostility and continued denial of a disability's permanence.

Stages of Family Adjustment

Resolving stress is an interfamily task and the family's success or failure in coping with crisis is prognostic. Intervention at crisis points by rehabilitation staff is assistive in reaching treatment goals and is based on an understanding of the adjustment process.

The therapist needs to note initial reactions to stress on the part of the family during the first few weeks, allowing for normal responses to crisis. Kaplan indicates that early case finding and intervention reduces the incidence of family disorder and breakdown. The crucial time for the development of healthy coping patterns is during the first 3–4 weeks.[1]

Christopherson outlines the chronological order of rehabilitation as follows: initially the family is vaguely aware of the implications of the illness or disability and their responses will depend on the quality of relationship within the family. During the reconstruction stage, the patient works to regain function through surgery or a physical/medical regimen. At this point, modification of social, sexual, vocational, and economic roles begins either on a temporarily or permanent basis. When all rehabilitation measures available have been utilized, the plateau stage begins. This may be the most difficult time in terms of family relationships, since all hope for a complete recovery is gone, economic and emotional resources have worn thin, and future decisions must be made concerning placement. Both the patient and family may experience severe emotional reactions at this point.[6]

Coping tasks to reduce stress vary significantly with each disease or disability. Reversing a trend to maladaptive coping and facilitating adaptive tasks requires knowledge of the disease process and patterns of adjustment specific to each.[1]

Initial and Continued Reactions

Brodland, in his study of burn patients, outlines both initial and continued reactions to a medical crisis. Initial reactions relevant to physical disability and medical illness include:

1. **Relief that the patient did not die or was not more severely hurt.**
2. **A primary concern for the recovery of the patient.**
3. **Fear and anxiety in dealing with patient behaviors, such as depression or hostility, the delirium of a brain injured patient, or the regression of the patient after surgery.**
4. **Distrust and hostility toward medical staff (concerning the diagnoses, the pain, the loss of the person as they know him/her).**

Continued reactions include:

1. Family disappointment at results that the medical staff may consider very good (appearance of grafting in burn cases, return of some function in persons with spinal cord injury or cerebral vascular accident).
2. A struggle for psychological preparation for the future (beginning to look at lifestyle change for the total family).
3. Concerns about continued pain, difficult treatment procedures.
4. **Trying to deal with the patient's disclosure of feelings such as frustration, grief (the family may discourage such ventilation to preserve its own comfort).**
5. **The family may cling to unrealistic optimism.**

Disordered Family Dynamics

Family Relationships

Families who are overprotective, highly anxious, and encourage dependent behaviors may prevent total rehabilitation. For example, a mother whose family is reared but enjoyed the mothering role may be tempted to encourage dependency in a handicapped adolescent or young adult.[8]

Litman found that the existence of close family ties and willingness of others to take care of the disabled often discouraged achievable levels of independence.[9] When the family sees the disabled as being more dependent or sicker than he or she is, efforts toward independence are discouraged. The patient is reinforced to behave according to family expectations, which often discourages the disabled from undergoing the rigors of treatment. This kind of overprotection by family members leads to gradual deterioration and loss of rehabilitation gains. Families may feel they know what is best for the family member and impose their plans and opinions without consideration of the patient's interests or personal goals. Such family responses result in patient regressions, depression, and feelings of helplessness and anxiety. A cross fire situation exists when the family, staff, and patient differ in their perceptions of the patient's ability to be independent.[9]

Families may hold certain attitudes and values toward disease and illness. They may equate cancer with death, hysterectomy with total eradication of a woman's role,[10] or brain damage as producing a permanent childlike state with no hope for a useful life. It may be difficult for the family to adjust and change their view of the patient as he or she progresses and gains independence and adaptive skills. Cultural or religious beliefs may prevent the patient or family from accepting the recommended treatment. They may view medical systems as untrustworthy and seek advice from lay consultants. Safilios-Rothschild states that the family may regard the disability or injury as punishment for a sin or evidence of guilt and thus may punish the patient by withdrawal or subtle criticism.[9]

A family may already be in crisis due to long standing resentments or interfamily control issues and anger at past wrongs (such as a spouse's infidelity). They may be punitive toward the patient, take control and prevent the patient from resuming major roles, or reject the relationship altogether. A traumatized family member may be unable to manage and may seek so much support from the patient that his or her emotional equilibrium is in jeopardy. They may absorb staff time to a deleterious degree or become ill themselves and demand equal treatment.

Versluys states that the patient can be placed in the position of dealing with personal adjustments and also supporting his or her family in their denial or anxiety states. The patient is sometimes put in a position of helping others, both family and friends, to relate to the new disability. Some families completely deny the permanence of the disability even after the patient has recognized the permanence of the handicapping or medical condition. Rather than hurt the family the patient allows the deception.[8]

Critical Family Issues

A critical dynamic occurs when family members do not support the medical regimen (ignoring dietary restrictions in diabetic or cardiac patients or bans on smoking and prescription for weight loss). Hoebel suggests that noncompliance to medical prescriptions is a family problem. In studies of coronary patients who continued to ignore risk factors like diet, exercise, smoking, and lack of relaxation, he found that spouses had not been meeting their husbands'/wives' medical needs and they were encouraged to assist their spouses in change through family treatment.[11]

Flights into activity accompany the inability of the family to face realities of illness, and to grieve. The family members may become involved in new activities, make changes in the family composition, move to a new home, take on a new job, and spend money on travel or unnecessary purchases. These activities support the denial, increase the family burdens, and absorb both emotional and physical resources needed to contend with stresses of illness and disability.[4]

Problems develop within the family constellation and affect the patient's morale when: *1)* the family fills the patient's roles on a permanent basis, *2)* the patient gets mixed messages concerning the continuation of a role, and *3)* the patient returns home and finds his or her roles distributed among family members, given away to others with no place of meaning left.[2,5,6] For example, the spouse finds another role partner or another child.

Kaplan speaks of discrepant coping in which the family members take opposing views concerning the long-term goals for the patient, including telling the patient the diagnosis, caring for the patient at home, handling of continued crisis, and even the values and meaning of medical treatment.[4] Family members may base decisions about the acceptance of rehabilitation or medical treatment goals on the advice of lay consultants. Such coping methods produce a lack of communication, prevent grieving, weaken and undermine family relationships, facilitate denial, and encourage avoidance behaviors. In addition, family members may not feel they are supported by other members during a crisis, leading to resentment and hostility.

Jaffe states that the family has a role in creating an environment which may both prevent or encourage exacerbation or maintenance of illness (as in systematic, neurological, cardiac disease). Individual response to psychosomatic disease may be influenced by family relationships and interfamily behavior patterns. Stressful family processes and life events are important causal factors in illness and health.[11]

In a review of studies on personality and family variables in relation to cancer, many studies supporting the association between cancer and loss of a person or object that is emotionally significant can be found. Thomas and Duszynski report that long-term data suggests that certain childhood family patterns can be linked with certain types of emotional and physical illness occurring many years later.[11]

Secondary Gain

Jaffe feels that secondary gain is present in the majority of illnesses and thus contributes to a reluctance or inability to get well and to the delayed recovery.[11] Minuchin suggests that a sick child plays an important role in the family pattern of conflict avoidance and that this is an important reinforcer of symptoms. The sick child may keep a couple from having to spend time together or keep a wife from her husband, since she needs to spend time nursing the child. Thus, the ill member can absorb the family's energy concentration and assist in conflict avoidance. Secondary gains for the patient may include care, affection and attention, the avoidance of responsibility, a desired dependent status, and control over the family.[8] Simonton and Simonton offer examples of the association of secondary gain with poor responses to cancer treatment.[11]

Other Problem Areas

1. Morbid preoccupation with the disease or disability such as cancer or paralysis with lack of focus on remaining assets and skills.[1,8]
2. Denial of the reality of the diagnosis and avoidance of those who refer to the facts and try to deal with them—for example, hostility towards staff.[9]
3. Efforts of some family members to prevent grieving in the service of denial.
4. Family suspicion toward medical staff, distrust of medical advice, and possible termination of treatment.[1,8] Such responses may be cultural or religious in nature and part of the family value system.
5. Family efforts (sometimes extreme) to keep diagnostic implications from the patient. This may be due to their own fear and inability to accept diagnostic implications.[4]
6. Family behaviors of open rejection. For example, missing treatment sessions, neglecting home care, refusal to seek out community resources, and avoidance of future planning with the patient[4] (such as refusal to order a wheelchair and necessary orthotic equipment, or neglecting to make the home accessible).
7. The displacement of family anger and resentment onto the physician and other professionals.

Adaptive Family Dynamics

Functional Attitudes

Lowery states that the quality of the interpersonal relationships within the family is far more important than the disability itself.[1] Others suggest that reaction of the family is the crucial determinant of the extent of rehabilitation from chronic illness.

Families who communicate attitudes of essential worth to the patient help to stabilize the self-concept, foster a positive attitude toward the future, and facilitate maintenance of rehabilitation gains.[1,9] Lewis and Bloom state that the presence of a supportive individual early in the diagnosis/treatment phase of breast cancer appears critical to psychological rehabilitation.[12] Hackett states that a good result in a myocardial infarction patient getting prompt treatment and good follow-up care is due to "the executive wife."[13] Dyk and Sutherland report a study of cancer surgery (colostomy) that indicates that the quality of the emotional response and support experienced by the patient within his/her family (especially the spouse) is the important factor in restoration of self-esteem, acceptance of the colostomy, and resocialization.[14]

The family's willingness to maintain or reestablish the patient's roles is an important motivator in rehabilitation. The family can influence the patient's maintenance of roles by: *1)* their ability to continue to relate to the patient and to see him or her in a major family role, thus contributing to the stability of the patient's self-concept, *2)* the willingness to carry out role tasks to allow the patient to continue in a major role, *3)* their communication of the patient's value in the organization of the family, and *4)* their identification of important and necessary roles the patient can contribute to, within the limits of dysfunction.

Barckley states that "families wonder what to bring the patient, but in the end the greatest gift comes from a loving heart and an understanding mind and an attitude that nothing can happen to the patient that the family's compassion and concern can't alleviate."[15]

Family Response To Long-Term Care

Issues Around Discharge

An interesting area for further study is how the family absorbs the patient and what assists them in doing so. The patient's personality, strength, and original social role in the family appears to be the best predictor of home success. The patient is more likely to return home if there are valid and responsible roles that can be performed.[16]

Safilios-Rothschild states that married women with children, even if severely disabled, are usually taken back by the family unit because they can maintain part of their usual role functions. The role tasks of the homemaker in planning, organization of family activities, participating in decision making and problem solving, and in enabling and encouraging other family members makes their presence a benefit. Active homemaking tasks can be carried out by others.[9]

Research shows that the single disabled person tends to be more independent in activities of daily living functions than the married disabled person. The greater the necessity to perform tasks and roles the greater the probability the disabled will use all their abilities to do so and will find ways to become as independent as their disability permits.[9]

The first year at home is critical for both the patient and the family. For example, both a spinal cord injured patient and the family may become depressed as they face the problem of mobility, isolation, and time restrictions due to extensive nursing care. Families may find their personal freedom restricted by responsibility for the patient and may find it difficult to meet needs for attention and companionship. Families may withdraw and isolate themselves. They may have their own negative feelings about the disability and may try to protect the patient and themselves from contact with others and possible rejection.[1, 4, 17] Diller states that there tends to be behavioral disruption when a patient having a cerebral vascular accident (CVA) returns home; the spouse or family has to adapt to new role responsibilities, there are problems finding economic support, there is a void in leisure time activities and difficulty in working alone to maintain physical function.[17] Family members may become overloaded, absent themselves from home, neglect any companionship roles, or exclude the patient from family gatherings.

When the patient is discharged, even a stable family may be overwhelmed by the magnitude of the disability. We cannot assume that families always have the intelligence, values, education, motivation, or interest to enable them as a unit to proceed as cooperative members of the rehabilitation team. For example, there is a higher incidence of wives deserting their husbands who are severely disabled, especially when there is an inability to perform vocational, economic, and sexual roles.[9]

Alienation and negative family attitudes may be due to emotional, economic, and energy drains and the need for support, empathy, and assistance with problem solving. Families run out of energy both physically and psychologically in a constant effort to be adequate. Some families have fewer resources than others and lower thresholds of tolerance to crisis and frustration. Such families may, with support and counseling, still be able to play a role in the lives of their disabled member.

Communication Patterns

Interfamily communication patterns may omit the disabled.[1, 18] Upon discharge, the patient may find that the family has developed a system where communication of vital family business takes place outside his or her presence. This alienates the patient from full family participation. Defective communication may be due to an effort not to burden the disabled member or resentment that the patient is no longer contributing to family role responsibilities. The disabled person may become the target for family hostility due to displacement of affection or projection concerning other failures and disappointments. Such secret communication may include planning for the patient without his or her knowledge. The result of these communication practices is to neutralize interfamily communication, since members are afraid to air their own feelings and needs or bring up controversial subjects (family economics, vacation planning, etc.).

Reactions of Family Members

Evidence suggests that spouses of chronically ill persons develop symptoms such as nervousness, fatigue, role tension, and depression to a degree equal or greater than that of the patient.[9, 11] The result may be precipitation of illness in the spouse influencing the patient's chances of returning home.

Spouse responses to patient illness show an increase in symptomatic levels of nervousness, fatigue, and role tension during illness.[12]

Wishnie, Hackett, and Cassem state that wives of coronary patients suffer from marked inhibition to deal with their feelings when the patient is discharged. They are unable to express the hostility that is a by-product of tension, fatigue, and lack of attention to their personal needs. They may feel guilty about the heart attack and about their personal needs and feelings and hold back grievances and frustrations in fear that such expression might bring on another myocardial infarction. The resulting behavior may be in the form of reaction formation such as overprotection or controlling behavior of a punitive nature. Such reactions result in familial discord.[19]

Dependent wives need to reverse lifelong patterns of overreliance upon their husbands. For example, they may insist that the husband with a recent CVA incident with aphasia continue to make important family decisions when they are incapable of doing so.

A spouse may grow to enjoy the leadership role and feelings of total control to the extent that the psychological growth of the patient is neutralized. The spouse may reinforce dependent, infantile behaviors and discourage resumption of major roles resulting in a parent-child relationship. For example, the spouse of an aphasic patient will "speak" for him and totally control all family activities. In addition, children out of mistaken kindness may insist on meeting every parential need and thus encourage dependency.[18]

Ways the Professional Can Help

Jaffe feels that treatment for disordered family dynamics should not be confined to the psychotherapist's office; rather, it should be an integral part of comprehensive medical care offered through members of the medical team. Treatment goals are to change the way the family works together, to help individual family members change the parts of their lives that contribute to stress, hinder rehabilitation, or lead to interfamily conflicts.[11]

Kaplan and Mearig see informal problem solving as the best way a professional can help. Their research project of providing a family support system through home visits and consistent interaction with the family allowed the staff to grasp the reality of "how would I deal with this situation in their place?"[20] Minuchin's strategy in treating psychosomatic illness in children is to help the patient to become more independent, to convince the family to be less concerned, less intrusive, and to focus less on the patient's physical status. Family members should also be encouraged to get back to normal functions and personal outlets and interests.[11] Diller suggests that spouses or families of aphasic stroke patients need to see value in small-term goals. They need to see changes that occur in small specific functions of daily living as stepping stones vital to the progress of the patient. Such attitudes can be transmitted to the family by the therapist.[17]

Staff Reactions

Rehabilitation staff are nurturing people. The intensity and the commitment demanded in long-term rehabilitation require the ability to give and to care. Staff may also develop rescue fantasies concerning certain patients. They tend to go into competition with the family. Staff may make value judgments concerning family relationships, note neurotic tendencies, call attention to the refusal to make necessary home adjustments or to order equipment on time. A stressed, hostile family may evoke counter hostility.[1, 8]

The staff, while caring for the patient and understanding the individual's process of accommodation, develops a tendency to expect the family to show instant ability to cope with the problems and adjustment of having a disabled family member.

Family Reactions

Families vary in their ability to assess the situation and make compromises in life plans. For example, the transfer of the patient from an acute setting to a rehabilitation unit may signal to the family that this is the end of their worries and the patient is getting better (or in reverse, that the doctors have given up). Families need better information—including explanation of the purpose of treatment procedures, operation of the rehabilitation unit, simple facts about the injury, understanding of the roles of each professional, where they may get important questions answered, and what approach would be most helpful to the patient in the rehabilitation process. The family may have mixed feelings toward the patient such as guilt, hostility, grief, and feelings of having lost a valued family member as they knew him or her. Not all families have the strength, resources, maturity, or stability to care daily for the severely disabled patient.[1, 4, 7]

Families may find they are in the way on the wards and in the treatment areas. Busy staff have little time for questions, anxieties, and fears. They may find the family intrusive, dependent, and feel that the patient/family interaction is harmful and not in the patient's best interests.

Families should not be made to feel guilty about their perceived inadequacies or they will be driven away from any involvement with the patient. Even if the family does not have the emotional or physical resources to take the patient into the home and even if the patient needs to be cared for in an institution, aspects of family relationships can be maintained. The family can be encouraged to visit and to take the patient home for weekends and holidays.

It is unrealistic to expect families to deal with these problems unaided. Families need help in thinking through values, broadening their outlook on the meaning of function and dysfunction, and recognizing that disability does not affect all capacities.[21] The family is also traumatized and should be treated simultaneously with the patient.

Counseling Guidelines

- — be available and therapeutic with the family.
- — identify and appreciate their feelings (grief, disappointment, etc.)[4]
- — encourage ventilation of "hidden" feelings without turning them off or judging.
- — counsel the family to stay in a holding pattern and not to undertake flights of activity.
- — keep the focus on the real crisis.[7]
- — deliver basic information useful to the family and patient.
- — help the family to see that their feelings are normal and acceptable.
- — provide praise for small accomplishments.[17]

- create bridges to appropriate community support systems.[7]
- explore the family's and patient's ideas for coping with problems. It is not always necessary to be the authority.
- provide programs and services that are responsive to family/patient reactions in the early stages of adjustment.
- discuss alternatives with the family that are realistic but focused on hopeful possibilities.
- provide information concerning procedures, simple facts about the injury, and the purpose of treatment methods.[7]
- work to prevent family rejection of the patient or alienation.
- discuss realistic aspects of being at home again.[19]
- listen without offering false hope, suggest that you are concerned with how they manage and how they feel.
- identify what is essential for the patient's welfare and what is not.
- help with setting limits for the patient and in understanding and dealing with difficult patient behaviors.[4]
- understand and respond to the family's fear of another incident (or another myocardial infarction, etc.).

Goals of treatment programming are to influence the remedial, supportive, and communicative skills within the family group. Programming objectives include: *1)* the development of a social/play arena where interpersonal relationships between patient and family can be strengthened through mutually shared activities and where relatives can learn to relate to their family member's change in health status, *2)* group problem solving sessions combining one or more families and focused both on the practical and emotional aspects of rehabilitation, *3)* groups combining one or more families focusing on encouragement of expression of patient/family feelings, and *4)* task-oriented groups focused on identifying and practicing new living skills through task assignment, within the hospital or in the community.[22]

Treatment Model Examples

D'Afflitti and Weitz designed a treatment group for stroke patients to focus on the difficulties of patients and their families in adjusting their lives to chronic disability, especially when it came time for discharge. The patients were engaged in treatment programs but the family members had difficulty with emotional acceptance of the patient's disability. This resulted in strained family relationships and negatively influenced discharge planning.

Goals of the family and patient group included: *1)* interfamily communication concerning feelings about the impact of the disability on family life, *2)* counseling to gain more realistic perceptions about the real limitations of the disability, *3)* encouragement of patients to share their feelings about the stroke (patient's fear of loss of control, loss of family, feelings of inadequacy), *4)* promotion of constructive adjustment to the disability, and *5)* encouragement of family and patients to use appropriate community resources and support systems.[23]

This treatment group model can be implemented within the hospital before discharge or as a follow-up group on an outpatient basis, located either at the hospital or at the homes of patients and their families. The model can be activity oriented and organized around social experiences. Handicapped role models or successful functioning family groups are facilitating.

Hoffman and Futterman describe an outpatient family support group developed by a psychologist and occupational therapist in an outpatient pediatric cancer treatment clinic. The therapeutic goals were to influence family coping tasks required in facing serious and possibly terminal illness in children. Initial goals included reinforcing the cohesiveness of the stressed family unit, preventing isolation and withdraw, encouraging involvement, and sharing with other families to facilitate a supportive environment. A play group was designed for the children/patients to counteract the oppressiveness of treatment, increase feelings of mastery, reaffirm identity, reduce feelings of vulnerability, provide an outlet for expression of anxiety, and release tension.[24]

This group model is applicable to other diagnostic groups such as in stroke or spinal cord injury follow-up clinics. Family task-oriented groups are interhospital groups with the goals of maintaining family role relationships. Emphasis is on programming to provide opportunities for families to interact with the handicapped member. Families are involved in dialogue concerning the adjustments to the disability, treatment issues, planning for discharge, and in social and recreational activities. Activities planned by staff, patients, and families help to reduce the tension a family feels on relating to the patient in an altered physical form or with a severe medical illness. Bridging activities include dinners prepared by patients or family, trips, game nights and parties, and entertainment by family and friends. These experiences allow the family to observe how the staff related to the patient and what they expect in independent behavior.

Jaffe discusses the value of family support groups in maintaining interfamily change; for example, fostering good health regimen such as weight loss, loyalty to prescribed diets, new communicative patterns, and role tasks. Family patterns may be rigid and resistant to change. Supportive family groups reinforce positive change.[11] Other areas ripe for the expansion of family and patient programming services include adult or geriatric day treatment centers, community clubs for the handicapped, the visiting nurses association, and community sponsored agencies delivering health services to the physically disabled, aged, and homebound.

Summary

Literature indicates that even concerned and stable families can be overwhelmed and alienated from the patient by the residual effects of physical injury and the long-term, progressive, and disabling results of chronic disease. Disordered and disorganized families can, with support and counseling, maintain contact with the patient and contribute to the maintenance of rehabilitation gains. Staff identification of functional and dysfunctional family dynamics as influencing remediation is of diagnostic significance and provides information for the development of treatment goals and programming. The staff, while caring for the patient and understanding trauma and behavioral reactions, should make allowances for the stressors that impinge on family structures.

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Premarital Counseling and the Couple with Disabilities: A Review and Recommendations

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Summary

Premarital counseling has historically been offered by physicians, clergy, and mental health workers who devoted only minimal time to psychological preparation for marriage. Today, in both group and couples counseling, increased communication is the major goal.

Achieving open communication and sexual compatibility between partners requires time, patience, and experience. Because couples with disabilities often enter marriage with little emotional or physical experience with the opposite sex, they are more susceptible to failed marriages. Lengthy premarital counseling is particularly important for these individuals. Counseling shared with couples who do not have disabilities, followed by private sessions focusing on typical issues and feelings, should be augmented by frank discussions about specific disabilities, financial management, sexual function, and reproduction. Post-marital counseling is also recommended.

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FOR MANY INDIVIDUALS, marriage is the most important developmental milestone in life. It signifies admission into adulthood, affirmation of and competency as a heterosexual human, and becoming part of the cultural tapestry woven by society. Yet, seemingly few people view marriage as a relationship for which preparation is necessary. It is generally assumed that the unprepared couple will be infused on the wedding day with some mystical ability that will enable them to easily and successfully deal with daily, intense interaction with a relative stranger. This wishful fantasy is nurtured from an early age as children are first told tales of hardship and struggle that end with marriage and living happily ever after and then see television or movie stories portraying marriage as a funny game or a relationship, as easy to sustain as kissing and making up. In their own families, children are apt to see conflict suppressed and denied or viewed as sufficient reason for dissolution of the marriage. It is the exceptional person who grows to regard conflict as an opportunity for growth and communication and marriage as a relationship requiring preparation and continued effort. The average individual has poorer preparation for marriage than for maintaining an automobile, which, ironically, comes with an owner's manual.

If this is an accurate picture of the physically and intellectually able individual who is contemplating marriage, what must it be like for the individual with physical impairments who must face many more hurdles in daily life and interpersonal interactions and often has had fewer preparatory experiences? All people would benefit from premarital preparation. For the person with a disability, it would indeed seem crucial.

History and Research

Premarital counseling has been traditionally undertaken by three groups: physicians, clergy, and mental health workers.[10] Physician involvement has been primarily in the area of premarital physical examinations, laboratory work, and sexual counseling, and has generally been viewed as centered on the individual, not the couple. Limited, if any, time has been given to psychological preparation for marriage. A brief review of pastoral and counseling literature indicates that prior to the mid-1960's attention was directed mainly at management of the dysfunctional couple. Premarital counseling of the untroubled couple was viewed as primarily intending to educate about sexual function and, occasionally in the pastoral literature, about the liturgical significance of marriage. The three groups in contact with the premarital couple could be said to be following the traditional medical model of diagnosis and treatment of pathology. Prevention of dysfunction was not as yet seen as a worthwhile or even possible approach to stabilizing marital and family life and decreasing the escalating rate of divorce.

Counseling aimed at prevention of marital dysfunction arose from the clergy and church related groups and was seen to parallel a concurrent rise in interest in preventive mental health among professional mental health workers.[4,12] Emphasis was then taken from the dysfunctional couple or individual and placed on the emotionally healthy premarital couple who wished to improve their present relationship and to develop skills enabling them to construct a firm marital bond. Such couples were mainly to be found in self-selected groups on university campuses and among religiously affiliated couples who sought church sanction for their marriages. Studies that have been conducted on the benefits of premarital counseling have drawn their subjects mainly from the university affiliated group and, unfortunately, results cannot be generalized.[4] Yet, empirical evidence would tend to support the benefits derived from skills learned before beginning a new role, and it remains for research to give scientific credibility to the practitioner's clinical judgment.

Literature dealing specifically with individuals having disabilities in the context of developmentally normal relationships, such as dating and marriage, is embryonic and virtually nonexistent.[13] Information must be culled from material dealing with disabled persons in abnormal environments or situations.[5,14] This article will attempt to make a conceptual link between the literature on premarital counseling of the "normal" couple and its potential use for the disabled couple.

Models of Premarital Counseling

Two methods of counseling the premarital couple are generally used: group counseling and conjoint counseling. There is some variability within each method, but each follows standard guidelines regarding setting, frequency of meetings and size (in group counseling). The one exception may be in a type of counseling that might more appropriately be called premarital education. Such groups are larger in size than counseling groups, require no preliminary screening of participants, and follow a didactic style of presentation with minimal opportunity for interaction within the couple, among couples, or between couples and counselor.[2] Such content oriented groups undoubtedly have a place in premarital preparation, but would not seem to offer opportunity for growth in skills necessary for successful interaction within the couple.

It is generally agreed among marital and premarital counselors that a major goal of counseling is increased communication skills.[1,4,7,8,9,10,12] Other goals frequently cited are: awareness of self and others,[7,9,10] increased ability to confront and resolve conflict,[2,7] and increased comfort with one's body and sexuality and that of the spouse.[5,8] Those favoring the group method of premarital counseling are not apt to mention the goal of physical and sexual awareness except in the context of sex education.

The group method of counseling is essentially a process oriented method which, nevertheless, lends itself to creative use of many techniques of counseling. The technique used most frequently is a combination of client-centered and social learning approaches. Couples are encouraged to openly discuss feelings on marriage related topics with the group as a whole and with the other in the premarital dyad. Time is taken to practice listening and speaking. This technique benefits from employment of two counselors, a man and a woman, who act as role models as well as facilitators. Often the couples are given "assignments" that reinforce the learning process or act as catalysts for discussion.

Van Zoost[12] used the above technique but added the use of videotape. Participants were able to appreciate the importance of nonverbal communication when the demonstration medium was played first with sound only then with the combined audio and visual components. Couples' conversations were privately recorded then played back to the couple with the counselor present and participating in the discussion. The couples' response to the use of videotapes was uniformly positive and indicated that visual feedback had "more impact" than oral feedback alone.

Advocates of group premarital counseling cite several benefits of this method, including time economy, reduced need for denial, rapid learning of communication skills, and opportunity to try alternate behaviors before a critical yet supportive peer group. Negative aspects of the group method include limited self-disclosure due to the group setting, domination of the group by one couple, and loss of relevant material due to absorption in another topic.[2]

Conjoint premarital counseling involves the formation of a counseling triad between the couple and a single counselor. Meadows and Taplin[7] utilized individual counseling prior to engaging the couple in conjoint counseling. The number of individual sessions varied from one to four and the move to conjoint sessions was made only when the clients felt they were ready. The individual sessions were described as "somewhat directive and cognitive" but their content and process were not discussed. The conjoint sessions focused on approaches to conflict resolution and increasing effective communication. The number of conjoint sessions varied from one to three. A questionnaire administered one month after completion of the counseling indicated that all couples felt that the experience had been beneficial, especially those who were no longer engaged. This is in interesting contrast to Stahmann and Hiebert,[10] whose theoretical framework espouses the view that counseling cannot change a couple's decision to marry. A possible explanation of this seeming contradiction may be that the couples seeking counseling in the Stahmann and Hiebert work were further along in the premarital period than the other couples, since Stahmann and Hiebert were offering pastoral counseling. Couples may not consult with clergy until ready to actually set a wedding date and may, therefore, have successfully resolved major conflicts. Another interesting point in the Meadows and Taplin study is the couples' response that they had found the conjoint sessions to be more "productive" than the individual sessions, but did not feel that all sessions should be conjoint. Again this may point to an early premarital period when there exists a strong need to protect the self from disclosure to the idealized future spouse.[11]

Stahmann and Hiebert have developed a useful framework for conceptualizing the dynamics of marriage and relating it to premarital counseling. In summary, they conceptualize marriage as beginning on a psychological level before the actual marriage takes place. Time adds to or thickens the "glue" (bonding or commitment) of the marriage. Marriage is a multidimensional relationship dependent on commitment, not ceremony, for legitimacy. As previously mentioned, Stahmann and Hiebert propose the theory that counseling cannot stop the "propulsion" toward marriage. Furthermore, they theorize that marriage is not an accidental or casual event, but a relationship toward which people are impelled by strong forces for change, growth, or healing. Their model of premarital counseling makes use of systems theory and follows a developmental model. The counselor explores both the families or origin and the history of the couple's relationship.

The "Dynamic Relationship History" makes use of factual information, which is made very concrete by visual representation on a blackboard or large paper, to explore areas of the relationship with which the couple have not dealt. During this session, the first or second of four or five, the counselor should assess: commitment and bonding, dependency needs, self-esteem and communication, uses of power, and, for clergy, religious practice. The structured format is nonthreatening and allows the couple to interact and therefore reveal feelings more rapidly than in a traditional therapy oriented counseling session.

The counselor conducts a "Family-of-Origin Exploration" in order to "look at the degree of separation that exists between each of the persons and their family of origin."[10, p. 70] Since psychological separation from the family of origin is necessary for adaptation to marriage and creation of a new family, the counselor is particularly interested in looking at relationships and attachments that have persisted into the present. Also important is looking closely at the parent marriages, since these are the primary models for the individuals now contemplating marriage. Insights the counselor has are shared with the couple.

Throughout the sessions the couple is encouraged to look closely at themselves and each other. Areas of conflict are brought into the open and the counselor acts as a facilitator of discussion and a resource for alternate ways of resolving conflict. The counselor also encourages the couple to consider future counseling six months to a year after marriage to explore feelings and strengthen the marital bond. The idea of postmarital counseling was introduced by Guldner,[3] who envisioned it as primary preventive marital counseling. He conceptualized the premarital couple as being "too starry eyed" to benefit from counseling. Premarital counseling should consist of wedding plans and contracting for postmarital counseling. An interval of at least six months after the wedding would allow the couple to face the realities of marriage and their relationship. However, Guldner did not discuss the couple whose desire to enrich their relationship was not connected with religious sanction of the marriage. This group may indeed be lost to counseling unless a relationship is developed with the counselor before the wedding.

The Client With a Disability

Premarital counseling of couples, one or both of whom has a physical disability, can be seen as an effort to enhance their opportunities for optimum quality of life. It is only recently that persons with disabilities have been removed from perpetual infantilization and allowed to participate in society as members who are capable of contributing to the general well-being. With this new attitude of full participation, these people are now marrying and taking full part in a culture that is designed to enhance the self-esteem of the couple and denigrate that of the single. Yet, many have had little opportunity to interact and communicate with the opposite sex on an equal status with those who have no disability. Individuals born with disabilities are often socially handicapped, which may lead them to grab onto marriage as a method for enhancing self-esteem and social ability. Even among those who enter marriage with self-esteem and ego intact, there may be a greater than average degree of idealization of the partner and of marriage. It seems that, as a group, persons with disabilities are "at risk" for divorce, and premarital counseling is a must to clarify issues pertinent to the couple and to assist the individuals to acquire skills of communication and self-awareness that are important in any marriage. Methods of premarital counseling for persons with disabilities need not differ from those used for others. What should differ is the length of the counseling and the topics discussed.

The premarital counseling should combine group techniques and conjoint counseling. The group counseling sessions should be of standard length and, if at all possible, be composed primarily of couples who have no disabilities. Interaction with these couples would give an opportunity for concerns to be viewed as part of the normal premarital developmental process. It would provide for the disabled couple all of the advantages of interaction with a peer group and provide modeling from an accepting counseling couple. In the group, social and human interaction can take place on many levels,[2] allowing the partner without a disability an opportunity to "practice" interaction as one who does have an impairment as well as to observe how the partner interacts with others. In essence, the group can provide a nonthreatening arena for testing and feedback on issues concerning "normalcy," conformity, and individuality. Group experience would be especially appropriate for those individuals who have spent all or most of their lives since impairment in a sheltered environment.

Conjoint counseling would begin upon completion of group counseling. Ideally, the conjoint counselor would be one of the counselors who had been involved in the group sessions. This would provide continuity for the couple and eliminate the need for an introductory period to establish a relationship with the counselor. If the counselor has not worked with the couple in group, then it is essential that the counselor know what has occurred in the group. This knowledge would help the counselor to validate the couple's experiences with the group and could act as a starting point for further discussion.

The frameworks and model established by Stahmann and Hiebert are excellent methods of helping the couple to come to a deeper understanding of themselves and their choice of marriage partner. It would be especially important to ascertain the previous dating and sexual histories of the couple as well as determining the presence or absence of pathological attachment to the family of origin. While such attachment may occur in either of the couple, it is more likely to occur in the member who has a disability.[14] If such an attachment becomes evident, it indicates a need for in-depth counseling.

While much of the counseling can proceed in an ordinary manner, there are several important topics that must be discussed with them particularly. These topics are: the disease entity or process that has led to the impairment or disability, financial management, sexual function, and reproduction.

A good grasp of the disease entity is important for the counselor and a necessity for the couple. Issues that must be discussed include how the impairment occurred (abruptly or slowly), the nature of the condition and the prognosis (static, progressive, terminal), the etiology of the condition (congenital, traumatic, secondary), and the effects of the condition on the functional ability of the individual (ambulation, mentation, sensory perception, stamina, nutrition, elimination). These issues, which may seem to be relatively minor inconveniences in life to those who live with them, may pose severe stumbling blocks to the ability of the person who has not experienced them to achieve closeness and bonding in the marriage. The counselor must help the couple to face and resolve any conflict between idealization of the helping potential and the reality of daily life in light of a dysfunctional body. Should the disease have a progressive course, the couple must verbalize this and begin to share and communicate their hopes and plans for the future.

Included in plans for the future are a realistic appraisal of financial matters. Chronic illness and impairment often impose special financial requirements. Will household help be needed now or in the future? Who is to be the principal wage earner? Have appropriate living arrangements been made? Will the couple need to live with either family of origin? Have all sources of income been explored? If not, why not? What distinguishes these questions from the ordinary exploration of financial questions common to all premarital counseling is the realization that financial independence is often more difficult to achieve and more difficult to maintain for persons with disabilities. Medications, hospitalizations, appliances, and so forth are constant expenditures that will not terminate and may very well escalate with the passage of time, regardless of the wage earner's increasing ability to earn. The couple should be assisted to face these issues and plan accordingly.

Sexual function may be a problem area for the couple, but it is more often imagined than real. A couple can be helped to explore their feelings about sexuality, sex, and its place in their marriage. In persons with severe disabilities, genital sex may not be possible. Has the couple become acquainted with each others bodies? What have been their sexual experiences, with others as well as each other? If they have not attempted sexual intercourse with each other, why not? Are the reasons religious, lack of opportunity, or is there an underlying fantasy on the part of one member that this marriage will be safe from sex? The counselor must be able to integrate sexual counseling into the premarital counseling.[8] Alternatives in position, stimulation, and penetration should be made available to couples whose prior experiences did not provide them. A frank discussion of sexuality and its varied expressions apart from sex must be a part of the counseling sessions.

Closely related to sexual expression, but not necessarily a part of it, is a discussion of the couple's reproductive abilities and plans. If the couple is able to reproduce, have they discussed having children? How would children affect their ability to work and play? If the disabling condition is hereditary, how do they feel about giving life to an individual who may inherit their physical difficulties? Issues such as methods of contraception should be discussed in detail, since ordinary methods may not be suitable for the couple. Have they discussed adoption or artificial insemination? Who have they consulted regarding genetics and reproduction? The couple should be supported in feeling that the decision is their's to make and their only obligation is to themselves, to communicate openly and honestly about this decision that others may want to make for them.

The couple should be strongly encouraged to return for further counseling. As is true with all couples, it may take several months before the reality of their marriage dims the stars in their eyes to an extent sufficient for clear vision. When the realities of life with physical disability have been experienced by the partner who has no disability or the realities of living with one's own disabilities plus another's, the marriage may hit a low that requires a trusted third party to return it to perspective. Issues with which the couple were unable to deal prior to marriage may now be more openly shared. All threat of losing the hoped for marriage are now gone and the couple can feel secure that the counselor is not attempting to dissuade them from an attempt at "normal" marriage. Postmarital counseling can strengthen bonds begun before marriage and help the couple to continue to communicate on an even deeper level.

Summary

Premarital counseling of persons with disabilities differs from other premarital counseling only in length and breadth. All people have needs, hopes, and romantic dreams. But the problems of persons with disabilities expose them to greater risk of marital dysfunction and breakdown. A sensitive, thoughtful approach to their concerns will enable them to begin marriage at least as well prepared as others.

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Value-Laden Beliefs and Principles for Rehabilitation

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Summary

The author offers for use and review the major principles that guide her study and research in the rehabilitation field. Beginning with the fundamental right of respect and encouragement regardless how severe a person's disability, the tenets progress through social and environmental influences, self-image, the relationship between the client's characteristics and his rehabilitation program, clients' activities within their communities, and client participation in rehabilitation planning and evaluation. Underlying each principle is an earnest belief that every individual is entitled to lead a life rich in opportunity, choice, participation, and achievement.

Rehabilitation Literature, September-October, 1981—*Beatrice A. Wright, Ph.D., was professor of psychology at the University of Kansas, Lawrence, and a teacher, researcher, writer, and consultant in the field of rehabilitation psychology.*

THE FOLLOWING makes explicit those "value-laden beliefs and principles" that have guided my work in rehabilitation as a field of study and service. They are offered as possible guidelines to others with the intent that they be examined and improved, and then kept in the forefront to remind and to prompt, to check and to challenge, lest they remain inactivated and submerged by the weight of social, political, and personal pressures of all sorts.

1. *Every individual needs respect and encouragement: the presence of a disability, no matter how severe, does not alter these fundamental rights.*

A person is entitled to the enrichment of life and the development of his or her abilities, whether these be great or small and whether the person has a long or short time to live. The person must not be led to devaluate the self or to give up hope. The person is not to remain neglected and deprived. Under no circumstance is the person to be treated as an "object" or "vegetable."

Biases that declare some groups to be more worthy or deserving of services than others lead to gross inequities and must be avoided. Life, increased mobility, and better communication skills are just as important to a 72-year-old as to a 12-year-old, to a mentally retarded person as to an average person, to a black person as to a white person, to a poor person as to a rich person.

The affirmation of human worth and dignity must not only be kept explicitly in the forefront when allocating limited resources. It should be reflected also in adequate case finding efforts so that no person who has a disability remains neglected.

2. *The severity of a handicap can be increased or diminished by environmental conditions.*

Although grammatical usage speaks of a "person's handicap," how handicapping a disability is depends to a great degree upon the characteristics of the person's environment. Thus, physical handicaps can be reduced by eliminating architectural barriers, interpersonal handicaps by overcoming devaluating social attitudes, educational handicaps by providing educational and training facilities, economic handicaps by extending work opportunities, emotional handicaps by enhancing family and group support.

It should be stressed that the rehabilitation process itself carries an important environmental impact. Professionals and others must continuously question whether present methods or systems of operation are always or maximally helpful. They should seek ways to improve the rehabilitation process as well as to support environmental changes in the home and community that reduce the severity of handicapping conditions.

3. *Issues of coping and adjusting to a disability cannot be validly considered without examining reality problems in the social and physical environment.*

It is to be stressed that the personal-affective life of the individual generally can be most effectively strengthened within the context of dealing with reality problems that exist in the social and physical environment rather than by treating feelings in an environmental vacuum. Supportive attitudes of family, friends, and professionals, as well as opportunities for satisfactory living offered by the community, facilitate the person's efforts to come to terms with the disability.

4. *The assets of the person must receive considerable attention in the rehabilitation effort.*

A person's healthy, physical, and mental attributes can become a basis for alleviating difficulties as well as for providing a source of gratification and enrichment of life. Special care must be taken to avoid overemphasis on the pathologic that leaves one inadequately sensitized to stabilizing and maturity inducing factors. Those attributes of the person that are healthy and promising must be supported and developed.

5. *The significance of a disability is affected by the person's feelings about the self and his or her situation.*

Feelings that often have to be worked through by a person who has incurred a disability are those of resentment, inferiority, guilt, loneliness, and being a burden; doubts about whether he or she will still be loved and accepted; worries about the future and how one will manage; and concern that one will be left behind. Such social-emotional concerns take time to resolve. When the person accepts the disability as personally nondevaluating and engages life positively, important rehabilitation goals have been reached.

6. *The active participation of the client in the planning and execution of the rehabilitation program is to be sought as fully as possible.*

Genuine respect for the client leads to the affirmation of the right, within very broad limits, to become actively engaged in the rehabilitation process and to make decisions that affect one's life. The client obviously also has information and ideas essential to rehabilitation progress that are not available to others.

Among the foremost consequences of active involvement on one's own behalf are the enhancing of the person's self-respect, initiative, and responsibility for carrying out decisions.

The principle requires that effort be made to determine the views of every client. Special effort will be necessary in those instances where a major problem of communication exists. Examples of such instances are deafness, aphasia, cerebral palsy, mental retardation, foreign speech, ghetto speech, and stuttering.

7. *The client is seen, not as an isolated individual, but as part of a larger group that includes other people, often the family.*

The problems of the client are intimately connected with those of the larger group of people whose welfare is shared. Therefore, early and active participation of such significant others as spouses, parents, siblings, and children are viewed as an important principle in the total rehabilitation process. Where the client is in fact alone, or is resistant toward including other people, this principle may remain inactivated.

8. *Because each person has unique characteristics and each situation its own properties, variability is required in rehabilitation plans.*

Grouping persons according to a specific disability must not lead to stereotyped inferences about them. Differences in the needs, abilities, and circumstances of persons with the same or a similar disability require diverse approaches rather than the inflexible application of procedures.

Differences in problems that stem from particular characteristics of particular groups further serve to underscore the need for variability in the process of rehabilitation.

9. *Predictor variables, based on group outcomes in rehabilitation, should be applied with caution to the individual case.*

At the present stage of knowledge the individual, if given a chance, often becomes the exception which, instead of proving the rule, challenges it. Assessment data, therefore, generally can be used more appropriately as an indication of present status and as a *guide to remediation* than as a prognosticator of future performance.

The direct application of group based predictor variables is not questioned in regard to the behavior of groups *qua* groups, as in voting or consumer behavior, but is questioned in regard to long-range decisions about a particular individual. Moreover, prediction based on the response of the individual to the rehabilitation process rather than on "group variables" encourages treatment corrections in accordance with continuing evaluation.

10. *All phases of rehabilitation have psychological aspects.*

All human beings react cognitively and emotionally to events that involve them. These reactions in turn affect the further course of those events. One is compelled, therefore, to recognize that psychological factors are ever-present and often crucial in all aspects of rehabilitation—medical, surgical, educational, social, vocational, as well as primarily psychological.

The psychologist (as well as other psychosocially versed professionals) can offer help to other professions. For example, psychologists are able to describe principles and procedures that help to motivate a client, review body-mind relationships that are important in rehabilitation, assess client attributes, evaluate psychological and behavioral consequences of particular environmental situations, demonstrate ways to resolve intra- and inter-group conflicts, and sensitize personnel to social-emotional aspects of professional-client relations.

11. *Interdisciplinary and interagency collaboration and coordination of services are essential.*

The needs of individual clients are so diverse, encompassing all problems that one might expect to encounter in human affairs, that a variety of services is necessary. Comprehensive rehabilitation, therefore, requires the effort of many professions and close working relations among the various kinds of rehabilitation agencies.

There is the persistent danger that the pressure to meet agency and professional needs most efficiently and conveniently will become the principal basis for coordinating services. To guard against this danger a clear and explicit focus on meeting client needs most effectively is required.

Because of the complexities in the system of services, the client needs a specified person to serve as "coordinator" or "advocate" in providing information and otherwise acting on his or her behalf. Such a person may come from a self-help group or any of the helping disciplines as appropriate, rather than routinely from a single profession.

12. *Self-help organizations are important allies in the rehabilitation effort.*

Self-help groups provide important programs and mutual support to their members. They also can aid rehabilitation personnel in the understanding of significant problems and the development of new directions in the rehabilitation field. More extensive collaboration between professionals and self-help groups can be expected to further shared objectives.

13. *In addition to the special problems of particular groups, rehabilitation clients commonly share certain problems by virtue of their disadvantaged and devalued position.*

Devaluation and disadvantagement are general life problems experienced by diverse groups: persons who have a physical, mental, or emotional disability; racial and religious minority groups; the poor, and so forth. These common problems give rise to important rehabilitation goals that are shared among socially and economically deprived groups.

Special problems stemming from the particular characteristics of particular groups are locomotion difficulties of persons with orthopedic disabilities, communication problems of those who have impaired hearing, addiction in the case of the drug user, malnutrition of the poor, intellectual deficits of the mentally retarded, and so on.

14. *It is essential that society as a whole strive continuously and persistently to provide the basic means toward the fulfillment of the lives of all its inhabitants, including those with disabilities.*

Among the obligations of society are the establishment of needed housing, schools, work opportunities, transportation, hospitals, recreational facilities, and other services. Professionals and others bear a responsibility in helping to meet these obligations by initiating and supporting appropriate legislation and programs.

Where national and community resources are limited, ways to make more effective use of them or to expand them must be sought. Inertia and resistance to change lead to ignoring pressing problems and must be replaced by a determined effort to work toward better solutions.

Extending the goals of rehabilitation to their ultimate implications requires that effort be directed toward the prevention of handicapping conditions. Improvement of health care, reduction of accidents, control of pollution, overcoming of prejudice, diminution of poverty, are all major societal responsibilities. Professionals and others cannot remain indifferent to them.

15. *Involvement of the client with the general life of the community is a fundamental principle guiding decisions concerning living arrangements and the use of resources.*

Under special circumstances, where vital considerations indicate the advisability of some form of institutional living, every effort should be made to help the resident participate in community activities and services. Involvement with the community also can be served by sharing institutional resources and activities with the public. Periodic visits on the part of the resident with family, friends, or in foster homes, should become established procedure. The location of institutions, within rather than outside communities, facilitates such integration.

The development of halfway houses and other interim steps that encourage community involvement is imperative. Housing designed to meet special needs should be available in the community to persons with disabilities.

The client who chooses specialized living arrangements should continue to have the option and opportunity to move elsewhere as circumstances permit. In the interest of life enrichment, the space of free movement of a person should be enlarged rather than restricted.

16. *People with disabilities, like all citizens, are entitled to participate in and contribute to the general life of the community.*

This means that persons who have a disability fulfill not just the role of consumers; they also have abilities and talents offering a significant resource that should be utilized for the betterment of the community. The removal of attitudinal and environmental barriers preventing full participation in community life must be pursued on many fronts, including research, public education, legislation, and other forms of action.

17. *Provision must be made for the effective dissemination of information concerning legislation and community offerings of potential benefit to persons with disabilities.*

Large numbers of persons with disabilities remain unaware of available services from which they could benefit. Professionals also are often unaware of them and thus do not serve adequately as sources for information and referral. Solution of the problem requires a variety of approaches by which both professionals and clients can be kept abreast of opportunities that might benefit clients should they choose to avail themselves of them.

18. *Basic research can profitably be guided by the question of usefulness in ameliorating problems, a vital consideration in rehabilitation fields.*

Basic research can be useful research in the sense of being oriented toward the alleviation and overcoming of problems faced in rehabilitation. The converse is also true: useful research can be basic research in the sense of advancing knowledge through the discovery of general principles that apply beyond the borders of the immediately presenting situation. It is misleading and stultifying to identify basic research with "pure" research, the unwitting assumption being that any guide to research other than that given by "knowledge for its own sake" renders it impure and somehow less basic.

It is, therefore, urged that the question of usefulness be regarded with favor as a guide to research. Basic research can profitably become real-life oriented in its conception and from its inception by considering usefulness as a value in the selection of problems, analysis of data, communication of results, and application of findings. In bridging the gap between theory and research, psychological concepts need to be examined and new ones introduced in the light of their usefulness in dealing with everyday life problems of persons who have disabilities.

19. *Persons with disabilities should be called upon to serve as co-planners, co-evaluators, and consultants to others, including professional persons.*

It is important that the rehabilitation field take advantage of the special knowledge and viewpoints of people who have disabilities. Such persons have had first-hand experience with the rehabilitation process and are directly involved with problems that personally affect them. Their ideas should be especially sought concerning ways in which rehabilitation services can be improved and the lives of people with disabilities enriched.

Organizations on behalf of persons having disabilities should make it a point to include representatives of client groups on their advisory boards. Examples of such organizations are rehabilitation centers, private and governmental health agencies, foundations, schools, and hospitals. Rehabilitation agencies should make certain that persons with disabilities serve in professional and nonprofessional capacities.

With respect to research on problems of rehabilitation, the special sensitivities and understandings of persons with disabilities can be utilized by having them serve as consultants and co-investigators.

20. *Continuing review of the contributions of those in rehabilitation within a framework of guiding principles that are themselves subject to review is an essential part of the self-correcting effort of science and the professions.*

The values and beliefs expressed in the foregoing set of principles need to be periodically reviewed for two main reasons. First, change in emphasis and content may be indicated by new knowledge and changing times. Secondly, specification as to how the principles can best be implemented requires constant examination and study if their effectiveness as guides in rehabilitation is to be increased.

In many cases, the sheer process of seriously examining a principle will reveal ways in which it is not being reflected in actual practice and also ways to improve the situation. Serious examination is directly available to everyone and when carried out in brainstorming group sessions can be especially productive.

Psychosocial Aspects of Invisible Disability

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DENNIS R. MAKI, Ph.D.

Summary

While persons with visible and invisible disabilities share certain psychosocial difficulties, people who have invisible disabilities also have a unique set of problems impeding their rehabilitation. Adjustment depends less on the severity of the disability or the degree of limitation than on the individual's perception of that disability and its limitations. Receiving less feedback than a person with a visible disability limits the individual's basis for his own acceptance and adaptation.

A slower rate of diagnosis, less social validation, fewer opportunities to associate with individuals who have the same disability, and uncertainty about the extent of the disability are especial problems associated with invisible disability. Clients who deny their condition's existence can be helped by a rehabilitationist who anticipates adjustment problems and prepares the client, suggests more frequent social involvement, and allows clients to mourn their unobservable loss.

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> John is a 32-year-old male with diabetes, which he has had since childhood. Although he is aware that his daily injection of insulin and regulation of his diet are imperative to the control of his disease, he frequently goes off his diet and at times has not taken his insulin as directed. He has been hospitalized numerous times due to complications of his condition caused in part by his nonadherence to his medical regime. He has been unable to hold down a regular job because of his frequent hospitalizations. Throughout his life he has felt he was "different" from other people, but it was a difference most people wouldn't know because there were no outward signs of disability. As a child, John attempted to hide his condition from others because he did not want to be thought of as different. Now, while he does not actively conceal his condition from others, neither does he talk with anyone about it. He learned long ago no one would understand.

THE PROCESS of rehabilitating individuals is psychosocial as well as physical. Disability affects not only how persons interact with their environment but how in turn those within the environment interact with persons with the disability.[1,2,11] Literature tends to emphasize the psychosocial aspects of visible disability,[3,6,9,13] while psychosocial aspects of invisible disabilities have been discussed only on a limited basis.

Although some psychosocial factors involved in rehabilitation of the person with invisible disability and the person with visible disability may be the same, it may also be proposed that there are psychosocial factors that may be unique to those persons with invisible disability and which may impede the rehabilitation process. This discussion is designed to increase the rehabilitationist's awareness of these factors and the potential problems they imply in order to enable the practitioner to facilitate optimal rehabilitation outcomes.

Defining Invisible Disability

Invisible disabilities may be defined as those conditions in which the medical condition is unapparent or not readily observed by the casual acquaintance. Some conditions that may be classified as invisible disabilities are diabetes, epilepsy, various types of cardiovascular disease (such as hypertension, arteriosclerosis, or other heart conditions), lupus, early stages of multiple sclerosis, kidney failure, and various types of cancer. Since these conditions provide no atypical appearance or no readily observable functional limitations to those interacting with the individual peripherally, there are no cues emitted causing others to alter behavior with regard to the individual with an invisible disability. Therefore the individual with the invisible disability also receives no feedback or cues for alteration of behavior.

The degree to which the disability remains invisible might be dependent upon the level of association with the individual. Although cues may not be observed by those knowing the individual peripherally, the more intimately involved a person becomes with the individual the more obvious the limitations may be. For example, the person with diabetes may exhibit no limitations to most people, although those living with the individual may observe the daily injection of insulin or the regulation of diet. Those more intimately involved over time with the person with multiple sclerosis may see the beginning invisible disability become visible as the functional limitations become more pronounced with progression of the disease. Other conditions, however, no matter how close the association with the individual, under normal circumstances offer no visible signs or cues. Such is the case of epilepsy, in which no visible cues or clues regarding the condition are apparent on a daily basis unless one observes a seizure. The same can be said for various types of cardiovascular disease—there are no visible signs unless the individual experiences an outward manifestation of the condition, such as a heart attack or stroke.

The unapparentness of limitation in invisible disability may be a unique element related to adjustment and acceptance of the limitation. This element distinguishes adaptation in invisible disability from adaptation to disability in which functional limitations are more readily apparent.

Scope of the Problem

Any individual with a disabling condition undergoes some revision of self-concept, some disruption of role pattern, and period of adjustment to the limitation.[15] The extent of adjustment may depend not so much on the extent of the disability or on the degree of functional limitation as on the individual's perception of the disability and the limitation the condition imposes.

The emphasis placed on success in our society in terms of finances and interpersonal relationships has filtered to other areas of life, such as physical "wholeness" and activity. Due to this seeming emphasis on perfection of somatic integrity, health may be seen as a valuable asset without which one is viewed as socially inferior. Although many factors may contribute to the individual's adaptation or adjustment to the limitations associated with their condition, their perception or misperception of the reactions of others may also be a crucial factor in their level of acceptance. The degree to which an individual is able to adapt, accept, and adjust to their functional limitations may depend greatly on their interactions with others within their environment and their interpretation of the reactions of others.

In interactions between most individuals, there are observed cues emitted, interpreted, and incorporated that bring about alterations of behavior in the interchange.[4,10] Individuals with obvious physical disabilities such as amputation of an extremity, paraplegia, or blindness, emit readily observable cues that others within the environment may utilize to alter their behavior or expectations in interacting with the individual. Although not all of these reactions may be positive, the individual with a visible disability may be forced to react and interact within the framework of reactions of others and utilize this feedback system to alter their behavior accordingly. Adaptation to limitations and therefore adjustment to disabling condition may be promoted more readily because of this feedback system revolving around interaction with the environment.[12]

Persons without readily observable physical disabilities, however, because of the unapparent limitation, may not be exposed to the environmental feedback system that creates for them the reality of their condition. This lack of feedback may lead to exclusion of awareness of limitations by the individual as well as others. Therefore, it might be proposed that individuals with invisible disability may be more likely to postpone the adaptation process and may be less willing or able to accept their condition realistically. The consequences of this postponement or nonacceptance can not only hinder rehabilitation efforts, but potentially could lead to further disability as well.

Problems Peculiar to Invisible Disability

A variety of factors distinguish invisible disability from visible disability, creating problems that can make the adjustment to visible disability more difficult. Factors such as delayed diagnosis, lack of social validation, lack of identification with role models, and lack of control might help account for the behavior of disabled persons and their perception of their condition, resultant feelings about self, and reaction to the environment.

The first distinction between visible and invisible disability is the rate of diagnosis. Persons exhibiting visible signs, such as paraplegia resulting from an accident, or amputation of a body part because of disease or injury, have a condition in which the need for medical help is immediately recognized by all involved. Medical attention therefore is usually received immediately. In the case of invisible disability, however, diagnosis may be delayed because of lack of recognition or acceptance of the vague symptoms that are exhibited. Because there aren't visible signs of disability, symptoms may be ignored by the individual as well as the family. Chest pain resulting from angina in heart conditions, for example, may be rationalized away as "only a case of indigestion." Weight loss in early diabetes may be attributed to "working too hard." Because of the covert nature of visible signs there may not be encouragement by the family to seek medical attention. The individual may, therefore, avoid seeking medical care thus delaying not only treatment, but acceptance of the condition as well.

When the individual chooses to seek medical care, because symptoms may be vague, medical personnel may not diagnose the condition immediately and may also attribute the symptoms to something other than a physical condition. Without the legitimization of symptoms through medical sanction, again not only treatment but acceptance of the condition by the individual and those around them may be delayed. When and if the condition is finally diagnosed, a system of denial may have already been established rather than a system for coping with the symptoms and thus the condition.

A second issue distinguishing visible disability from invisible disability is the degree of social validation. Social role theory is defined as a status in which a collection of rights and duties is put into effect.[5] People within society therefore interact and react according to learned expectations of behavior. Persons with visible signs of disability may be assigned a different collection of rights and duties, however, and expectations of those within the environment may therefore be altered accordingly. For instance, an individual with a bilateral lower limb prosthesis wouldn't be expected to run up three flights of stairs if an elevator were available, nor would a person who is blind be expected to know the location of all furniture within an unfamiliar room.

However, in the case of invisible disability, where others may not perceive that there is a disability present which may restrict certain behaviors, the situation may involve frustration of normal expectations, provoking embarrassment or rejection in the extreme. Behavior of the individual may be misinterpreted by others in the environment, which may result in negative feedback to the individual with invisible disability. As an example, a man with a heart condition may be restricted as to the type and amount of physical activity he may engage in. Yet to the casual observer unaware of his functional limitation he may be criticized for allowing his wife and daughter to do all the heavy yard work "while he just sits there." In order to avoid negative social reaction, individuals with invisible disability may choose to ignore the functional limitation, carrying on activities as normal to the detriment of the condition.

The third aspect of invisible disability that gives it special character may be the affiliation with others having similar conditions. Although this type of identification may not be actively sought out by individuals with a visibly apparent disability, it is not difficult for them to observe others within the environment with conditions similar to their own, giving the individual some yardstick by which to measure their own progress. Behaviors of persons with conditions similar to their own may be observed in a variety of social situations, which may help the individual with visible disability to make decisions regarding their own conduct of behavior, and may even serve as a motivating factor toward their own adaptation to their limitations.

Persons with conditions that don't exhibit visible signs, however, are not able to avail themselves to easily recognizable peers or to the private comradery that may be based on their shared condition. Therefore, they have no ready means for observation of others' behavior, which might be utilized in learning to adapt to their own disability.

Another consideration distinguishing visible from invisible disability is the lack of control and finality that may be experienced by those persons with invisible disability. Persons at the onset of any disability may feel some sense of lack of control; however, persons with visible disability have a visible loss that can be confirmed and established. Although they may experience the possibility of complications associated with their disability or further loss due to another disabling condition, their initial loss is generally established. This would enable them to begin to learn new skills, compensating for those lost, and learn to adapt their life-style accordingly. For example, a person with spinal cord injury only experiences loss of the use of their lower extremities once. Although other problems such as urinary tract infection or decubitus ulcers may be a continuing source of discomfort related to their disability, such complications are reversible, and the initial loss of use of their legs has already been established.

This same sense of establishment and confirmation of loss may not, however, be experienced by those persons with invisible disability. Since the individual with invisible disability doesn't have a loss they can readily see, there may be uncertainty as to the extent of their loss and what they might do to adapt, and to prevent further loss from occurring. Persons with diabetes, no matter how carefully they adhere to their treatment regime, may still experience further disability (such as diabetic retinopathy) as a result of their condition. Such a complication is not only irreversible but causes considerable further loss as well. The person with epilepsy, although carefully taking the prescribed medication, may still have a seizure in a public work setting. The person with multiple sclerosis, despite alteration of activities, may still experience decline of their physical condition with increasing functional limitation. Individuals with progressive disease such as cancer or renal failure may experience continued loss of function as their disease progresses and limitations become more visible. This potential for loss demands the individual to be in a constant state of adjustment and adaptation to new functional limitations. Such lack of clarification or finality of loss may be a cause of lack of resolution of loss, and subsequently make acceptance of the invisible disability more difficult.

Use of Denial in Invisible Disability

When the disabled person chooses not to recognize the limitations imposed by a condition, we speak of "denial." When the individual recognizes the limitations, but refuses to adhere to them, this might be a form of denial as well, and may be viewed as a sign of nonacceptance. Perhaps the most pronounced and potentially dangerous differences between visible and invisible disability is the ability to hide the condition itself.

Due to the lack of visible reminders, persons with invisible disabilities are better able to deny their disability, thereby postponing adaptation and learning of skills compatible with their condition. However, because of lack of visible reminders, persons with invisible disability are also better able to hide their condition from others. Karl Menninger said, "It is not the false hope of eventual recovery but the possibility of masking the defect which makes clients resistive to rehabilitation measures."[7]

If a person with an invisible disability has chosen to hide the condition through denial of symptoms or denial of limitations, the individual may also then live in fear of discovery, since there is no sense of control of finality to their condition. Discovery of the condition by others may be anxiety provoking if the person with invisible disability fears the reaction of others to the disability. Such fear may be based on real or imagined perceptions and expectation of averse or negative reactions. The individual may have observed negative social input by persons without disabilities when interacting with those having visible disabilities. They may fear derogation, rejection, or being classified as "different," which could result in social isolation. The individual with the invisible disability may perceive discovery of the disability as loss of status as a unique individual and feel they will be treated as a member of a derogated class to which certain qualities are attributed because of the disability. The individual's fears may also be based upon their own feelings as they project onto others their own negative reactions to visibly disabled persons. No matter what the cause, the person with an invisible disability may react to this fear by denying or ignoring the condition, thus ignoring any limitations and carrying on as before. Because the individual may be strongly influenced by their perception of the roles and expectations of others, they may idealize normal standards and become more determined to prove their lack of limitation by pushing themselves beyond their normal capacity.

Acceptance of the Sick Role in the Adaptation Process

Acceptance of the sick role, especially in the inital stages of a disabling condition, may be the first step in adaptation. In the critical periods of any condition, acceptance of the sick role may be necessary for treatment. By accepting the sick role, individuals admit to themselves and others that they have limitations, and treatment can be started to prevent further limitations and complications so that the individual may adapt their life-style accordingly and return to the outside world as a functioning member of society.

The sick role entails the following characteristics:

1. The individual is exempt from normal responsibility.
2. The individual is not expected to rid oneself of the disorder by will power or to take care of oneself.
3. The individual should want to get well.
4. The individual should seek medical advice and cooperate with medical authority.[8]

By virtue of the condition, the person with visible disability may be better able to accept this role and thus begin the adaptive process. The individual who sustains a traumatic amputation as a result of an accident has no choice but to seek medical care immediately. The person who has hemiplegia as a result of a stroke exhibits visible cues, in which no one would expect the person to carry on daily activities as before without considerable medical attention and rehabilitation. No one would expect a person with a spinal cord injury to use sheer will power in order to walk again.

Invisible disability, however, gives no clear visible cues. The person with invisible disability is better able to avoid the sick role because of the lack of cues and attendant lack of social reinforcement for accepting the role. If the individual does try to accept the sick role, because of the lack of visible cues, behavior may be misinterpreted and even criticized by outside observers. Behavior may be perceived as malingering. Because limitations aren't readily apparent, the individual may not be viewed as exempt from responsibilities and may be regarded as lazy or unsociable. The individual with an invisible disability may be chided by others until they ignore or exceed the limitation imposed by the condition, thus causing the potential for additional physical damage.

Because of the invisible nature of the disability, others may expect the individual to rid himself of the disorder and may dismiss reluctance to be in various activities as "being all in his head" or "only a matter of feeling sorry for himself and wanting attention." Others may express the view that "she could really do more if she only wanted to" or "she looks healthy enough to me." Such attitudes by others further discourage the individual with invisible disabilities from seeking medical care and treatment or from adhering to limitations of the condition. Such outside pressures may eventually convince the individual that they truly aren't ill, fostering defense mechanisms of denial.

A psychological construct related to the behavioral presumptions of the sick role is the "requirement of mourning."[14] If an individual loses a cherished person or object, or has an observable loss of body part or function, mourning is condoned. However, in order to mourn one must first define what has been lost. The person with invisible disabilities has a loss that is less tangible. There is, therefore, lack of social support for grieving, another impediment to adjustment on the part of the individual with the disability.

Implications for the Rehabilitationist

The rehabilitationist, in working with the person with an invisible disability, must be aware of the psychodynamics related to the individual's adaptive process and offer anticipatory guidance in order to assist the individual in acceptance of and adjustment to any limitations. The rehabilitationist should not minimize the individual's reaction to the condition merely because the loss is less observable and limitations less apparent.

By being aware of the complexities of the social situation the rehabilitationist might work with the client by helping to identify reality factors and appraise the disability realistically, so as not to exaggerate its negative consequences. Through understanding that the person with invisible disability may perceive himself as different from others and may present himself that way, the rehabilitationist can offer suggestions to assist the individual to increase positive interaction with others.

Since a central core of psychological aspects of invisible disability may have to do with the psychodynamics of loss and the extent to which the individual was permitted to declare and mourn a loss, the rehabilitationist must assist the client in mourning any loss outwardly, thus bringing acceptance of the condition and subsequent limitations.

The goal of the rehabilitationist in working with the person with invisible disability becomes broader than merely assisting the individual to return as a productive member of society, a role that the individual may never have left. Perhaps a more important goal in the rehabilitation of clients with invisible disability is that of prevention. Through increased awareness of the problems in adaptation and adjustment for the person with invisible disability, the rehabilitationist may be better able to intervene early, thus helping to prevent maladaptive behavior that can lead to further disability and subsequent increased functional limitation.

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Sexual Dysfunction Associated with Physical Disability: A Treatment Guide for the Rehabilitation Practitioner

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Summary

Adaptation to sexual dysfunction associated with physical disability depends more heavily on the individual's pre-disability sexual knowledge, attitudes, experience, and general psychological adjustment than on the actual disability. A combination of organic and physical factors, a previous sexual difficulty, inadequate sex education, emotional distrust between partners, and internal attitudes about sex contribute to sexual dysfunction. Health practitioners need to assess their own sexual attitudes and knowledge before discussing patients' sexual habits or suggesting alternative forms of sexual expression. Practitioners who convey belief in their patient's right and ability to be sexual will encourage sexual expression and alleviate problems that might otherwise require intensive therapy.

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Introduction

NUMEROUS PHYSICAL DISABILITIES and organic disorders can affect an individual's sexuality, including damage to nervous system controls over the sexual response cycle (arousal, orgasm), circulatory disorders, liver and kidney disease, pain, weakness, physical exhaustion, and the side effects of medication. Failure to adjust psychologically to a physical disability and to the sexual dysfunction which sometimes accompanies it often implies a future of extremely unsatisfying sexual abstinence for the patient. The rehabilitation practitioner is in a unique position to effect both physical and interpersonal growth, and can thus prevent such undesirable outcomes by becoming a rehabilitative agent in the area of sexuality. Because human sexuality is such a delicate, value-laden issue which generates intense emotional responses in most individuals, and because of societal constraints which prevent open, matter-of-fact discussion of sexuality, it may be difficult for practitioner and patient to communicate about successful sexual functioning, as well as about sexual difficulty.

The present article discusses the psychological factors which must be taken into account by rehabilitation practitioners wishing to undertake interventions in the area of human sexuality. It is predicated on the assumption that the patient's post-disability sexual adaptation has more to do with his/her pre-disability adjustment (that is, level of sexual knowledge, sexual attitudes and experiences, and general psychological adjustment) than with the disability per se. We begin with an examination of the view, tacitly held by many health practitioners, that disability ends both sexual desire and the capacity for sexual behavior. We then examine common causes of sexual dysfunction in all persons, disabled as well as non-disabled, under the assumption that knowledge of the most common etiologies of sexual difficulty will cause the rehabilitation practitioner to become more attuned to such factors in the assessment and treatment of sexual dysfunction in patients who *happen to have* physical disabilities. Next, we present a step-by-step discussion of the intervention strategies which may be employed by rehabilitation staff who deal with sexual problems in disabled patients (specific reference texts for use by both practitioner and patient are listed in conjunction with each topic discussed). The article concludes with a brief consideration of those sexual difficulties which necessitate referral to a specialist. Methods for selecting a competent and appropriate sex therapist are also enumerated.

Examination of the Traditional View that Disability Ends Sexuality

An unspoken but nevertheless apparent cultural belief in America is that the right to be a sexual person is reserved for young, physically flawless people; only such mythical models are thought to be capable of, or entitled to, sexual feelings.[9] But physical disability often causes dramatic changes in an individual's physical appearance. Consider, for example, the post-mastectomy patient with unsightly scar tissue, the ostomate with a visable fecal waste bag attached to the abdomen, or the patient with spinal cord injury who uses a wheelchair. Many patients having physical disabilities receive explicit or implicit messages from health practitioners that their disability has removed the *physiological possibility* for sexual response:

> Arthur, with multiple sclerosis, had been fitted with an indwelling catheter. "Should I take it out for sex?" he asked his GP. "Best not to bother with sex," he'd been told. "You'll probably find it too tiring . . ."[7, p. 1089]

While it is true that drastic organic changes such as spinal cord transection may remove the capacity for genital arousal and orgasm, the rest of the body and psyche often remain intact.[18,20] To define sexuality as an erect penis, a lubricated vagina, or an orgasmic response thus imposes a severe limitation on a function which has a myriad of possible manifestations.

Related to the message that disability removes the capacity for sexual behavior is the message that disability removes the *desire* to be sexual. Consider, for example, the terminal cancer patient who still wishes to pursue a sexual relationship with his or her spouse despite colostomy, total bed confinement, and catheterization. It is not uncommon for health practitioners to respond to such a scenario with disapproval and disgust, due to the belief that such a patient "should be worrying about dying, not sex."

Additionally, practitioners may inadvertently reinforce the idea already held by many patients that sexual activity will exacerbate a preexisting physical problem. This point has particular relevance for practitioners working in the chronic pain clinic. Here, the patient has passed well beyond the acute phase of tissue damage where physical activity might indeed reinjure a healing area. But due to fear of pain and/or additional injury, such patients frequently remain largely inactive, guarding the once-injured area to such an extent that muscular tension and atrophy result. Such patients should be encouraged to engage in physical activity (including sexual activity) as a means for reducing tension and strengthening muscles.

In sum, the physically disabled patient has both the right to want to remain a sexual being, and the physiological potential to express his or her sexuality behaviorally. Health practitioners can be among the first to help patients assert such rights, or they can squelch this powerful source of gratification through active disapproval or through passive unwillingness to discuss sexual matters openly with patients.

Common Causes of Sexual Problems and/or Dysfunctions

Organic Factors. There are a number of organic factors which can contribute to the development of a sexual dysfunction. In most cases, however, these factors are not solely responsible for the disorder. A sexual dysfunction which appears initially to have a purely organic etiology is often exacerbated by such psychological factors as humiliation, frustration, or anxiety. Those organic factors which may affect sexual function include physical fatigue, drug use and abuse, chronic kidney or liver dysfunction, vascular disease, endocrine disorders (such as diabetes), and neurological disorders (such as multiple sclerosis). Drugs most likely to disrupt the sexual response cycle include alcohol, other central nervous system depressants and stimulants, narcotics, antihypertensive medications, high doses of antihistamines, antidepressants, and antipsychotics.[19,21] As age increases, the intensity and quality of an individual's sexual responses may change, and sexual desire may gradually diminish. In men, erection may take longer to achieve, ejaculation may be less forceful, and the time between orgasms may increase. In women, vaginal lubrication and orgasmic intensity may lessen. At no point, however, does age alone render a person physically incapable of enjoying all aspects of sexual function. Moreover, although physical disability (paraplegia, quadriplegia, arthritis, cancer, chronic pain conditions, or chronic heart and lung disease) may necessitate a drastic change in sexual technique, it need not preclude all options for sexual pleasure.

High Incidence Premorbid Sexual Dysfunction. Statistical evaluations of normative sexual behavior suggest that sexual difficulty is by no means unusual in the course of an average lifetime. Data from Masters and

Johnson,[16] for example, indicate that approximately 50 percent of all married couples will experience a sexual problem at least once during the marital relationship. Moreover, investigations of premorbid sexual functioning among nonpsychiatric medical patients have revealed significant dysfunction not attributable to the onset of illness. For example, Warbrek and Burchell[22] interviewed 131 male patients hospitalized for an acute myocardial infarction regarding their level of sexual functioning before the heart attack. These patients reported that, prior to the onset of illness, 64 percent had erectile failure, 28 percent had a significant (>50%) decrease in sexual frequency, and 8 percent had premature ejaculation. It is thus statistically likely that the typical rehabilitation patient has experienced a sexual difficulty in the past, and that this difficulty has carried over to affect present functioning, at least in terms of its historical significance for the patient.

Lack of Adequate Sexual Education. A factor which frequently contributes to the development of a sexual dysfunction is lack of adequate sexual education. Courses in sex education offered through the public school system place primary emphasis on reproduction, birth control, and the prevention of venereal disease; aspects of sexuality related to the giving or receiving of pleasure are seldom discussed. As a consequence, many individuals come to evaluate their own behavior in light of the sexual myths and unrealistic performance ideals which have been acquired in place of accurate knowledge. Frequently, a brief statement to the effect that a patient's behavior is, statistically speaking, quite normal, can remove enormous anxiety and distress (e.g., "Actually, what you describe as 'premature ejaculation' is above the average amount of time for most men to thrust. The majority of men who thrust steadily inside the vagina will ejaculate within two minutes."). Similarly, all that may be required to "treat" some sexual problems is a brief statement indicating that an individual is experiencing a normal physiological change which affects the sexual response cycle, but is unrelated to disability (e.g., "It takes men longer to achieve an erection as they get older. The gradual changes you've noticed in this response over the past few years are a result of aging, not of your physical disability").

Dyadic Factors. Certain aspects of the relationship between a patient and his or her partner can also contribute to the development of sexual problems.[13] Dyadic factors which are frequently present in the sexually dysfunctional couple include emotional distrust of one or both partners for the other, fear of rejection, anger regarding expectations that have gone unmet, dyadic power struggles, and physical or emotional repugnance on the part of one partner for the other. (Specifically in this regard be alert to the possibility that a recently acquired physical disability may be used by the patient as an excuse for avoiding sexual relations with a partner who had been found physically unattractive prior to the onset of disability.) In addition, poor communication regarding sexual feelings and desires pervades most sexually dysfunctional relationships at both global and specific levels. Couples who possess adequate communication skills in other areas of the relationship may hesitate to articulate sexual desires because of the belief that overt discussion of these feelings will take the "romance" or the "spontaneity" out of sex. In fact, such concerns often mask deeper fears of taking responsibility for one's own sexual feelings and behavior. Moreover, such assertions often reflect the real or imagined possibility that sexual self-disclosure will be used by the other partner to sabotage the relationship, or to justify rejection of the partner making the disclosure. In sum, the practitioner who addresses specific sexual concerns in the patient with a physical disability must always be alert to the possibility that dyadic conflict is causing or exacerbating what has been described by the couple as a "strictly sexual problem."

Internal Psychological Conflict. Individual psychological factors can also influence the development of sexual dysfunction. An individual's basic attitudes about sexuality (its pleasantness/unpleasantness, its rightness/wrongness, and the purpose for which it should be undertaken) are typically learned in the early family environment and carried into adulthood.[12] Some individuals acquire the belief that sexual behavior is morally wrong, that it is an unpleasant but necessary evil, or that it is intended exclusively for procreation. Others grow up with less extreme but nevertheless negative feelings about their sexuality: "If I were really masculine I wouldn't have problems with my erection, regardless of how I felt about the woman I was with," or, "I'm bored with always having sex in the missionary position, but the woman-on-top position is perverted." Such attitudes about one's own sexual feelings and behavior can severely impair an individual's capacity for enjoyment. Sometimes the health practitioner must confront the patient with such attitudes and, where appropriate, present alternative ways of viewing sexuality. One study, which assessed the attitudes of spinal cord injured outpatients toward a range of sexual behaviors both before and after participation in a sexual counseling program, demonstrated that patients left the program with a more permissive range of attitudes regarding sexual function, and evaluated the program as helpful in their overall sexual adjustment.[17] In addition to negative feelings about sexuality acquired during childhood, traumatic or unpleasant sexual experiences at any age may cause an individual to have ambivalent feelings and/or maladaptive behavioral responses in later sexual situations. Systematic exploration of the feelings associated with such experiences is often the first step in helping the individual to differentiate between a painful past and the potentially fulfilling sexual opportunities of the present.

The Practitioner's Own Sexual Adjustment

While it is generally the case that a health care provider should assess his or her own level of comfort in working with a specific disorder or population, this is particularly true in the area of sexual counseling and rehabilitation. Important factors to consider in conducting such a self-evaluation include: *1)* one's knowledge of basic sexual facts, including one's understanding of sexual anatomy and the physiology of the human sexual response cycle,[3,5] *2)* one's knowledge of statistical norms related to sexual behavior (i.e., the incidence of sexually variant behaviors), and *3)* one's knowledge of the mechanisms involved in sexual behaviors other than penis-in-vagina intercourse. Additionally, it is essential to be cognizant of the impact that one's own level of comfort with sexuality has on the effectiveness of interventions with patients. The history of, and satisfaction derived from, one's own sexual relationships will make the exploration of patients' problems less difficult. Finally, because there is such a wide variety of sexual behaviors in which the general population engages (e.g., heterosexuality, homosexuality, masturbation, oral stimulation, and so on), it is important for the practitioner to be aware of his or her own level of comfort in either acknowledging a particular sexual variation to be part of a patient's behavioral repertoire, or in suggesting possible alternatives for sexual expression to a patient.

The Role of the Rehabilitation Practitioner in Facilitating Change

Although the rehabilitation practitioner does not usually undertake psychotherapeutic interventions with patients, many sexual problems respond readily to more basic forms of treatment. Annon,[1] for example, asserts that the majority of sexual problems (not specific to those with physical disabilities) can be solved through the giving of permission to be sexual, and through the provision of limited information and specific suggestions for minor behavioral change. He further asserts that only a small minority of people require intensive psychotherapy for sexual difficulties. This conceptualization implies that the rehabilitation practitioner can effectively and appropriately treat most patients who need to adjust their method of sexual expression due to a physical disability.

What follows is a step-by-step discussion of how such treatment should be undertaken, beginning with instructions for sexual history-taking and concluding with methods for introducing the patient to techniques of sexual stimulation other than penis-in-vagina intercourse.

The Importance of Pre-Disability History in Accurate Assessment

Patients have a marked tendency to claim that the onset of sexual dysfunction was concurrent with the onset of physical disability. But research suggests that an individual's success in coping with life stresses prior to disability is associated with both the likelihood and the severity of post disability-related problems in adjustment.[4] This indicates that the patient's belief that disability has played a causal role in bringing about sexual dysfunction may be inaccurate. Because practitioners are often less willing to probe the accuracy of patients' interpretations in the area of sexual adjustment, rehabilitation staff may too readily agree with an inaccurate assessment of the origins of a sexual problem.

Knowledge of a patient's sexual history can enhance the practitioner's understanding of current sexual adjustment in three ways. First, careful historical assessment provides information regarding the individual's level of sexual knowledge. Inadequate understanding of the physiological changes which accompany various stages of the sexual response cycle, or the absence of basic knowledge regarding male and female genital anatomy, can be responsible for sexual dysfunction in individuals who are otherwise well adjusted and happy. Adequate assessment of the patient's level of sexual knowledge thus becomes essential in identifying those aspects of a problem which may be wholly treatable through an educational intervention. A second way in which understanding of current functioning can be enhanced by good history-taking has to do with assessing the patient's past sexual experience. Because explicit discussion of sexual behaviors and preferences is in violation of widely held cultural norms, all persons (including health practitioners) have a natural tendency to assume that the majority of people with whom they come into contact have had sexual experiences similar to their own. But variety in sexual behavior is the norm rather than the exception. Practitioners who fail to recognize areas in which their own past behavior diverges from that of their patients' will find the channels of communication regarding sexual concerns rapidly closed. Consider, for example, the practitioner who presumes at the outset of an interview that the patient with whom he/she is speaking has had exclusively heterosexual contacts in the past. Such a presumption will readily convey an implicit message to the patient that concerns related to homosexual experiences and desires are not an acceptable topic for discussion.

Because the onset of physical disability frequently necessitates modification in the manner in which an individual seeks sexual gratification, the practitioner needs to know, before planning an intervention, what limits might be imposed on the treatment plan by the patient's own value and belief system. Thus, a third important function of adequate history-taking has to do with assessment of the patient's current attitudes regarding the "rightness/wrongness" or acceptability of various sexual behaviors and feelings. Careful questioning about the atmosphere of the early home environment, the nature of sexual information received from parents, and the manner in which physical affection was displayed in the home can be extremely useful areas to probe in an effort to assess current attitudes and values.

Permission Giving. The giving of permission is accomplished by sending both verbal and nonverbal messages to the patient that it is OK: *1)* to have questions about sex, *2)* to want to continue to be a sexual person following disability, and *3)* to want to learn about alternative means for sexual expression. Nonverbal means for conveying these messages might include having books openly displayed which deal with sexual alternatives for persons with physical disabilities (see, for example, Mooney, Cole, and Chilgren,[18] Hale,[8] Heslinga and others,[10] and Ayrault[2]). Permission giving can also involve simply providing the patient (and his or her partner) the privacy required to be sexual in an institutional setting. A number of cancer wards, for example, have instituted informal policies whereby a sign is hung on the patient's door during such "private" times. Finally, giving permission can mean helping to explode the myth that sexual expression is appropriate only for young, healthy, and physically "able bodied" individuals. The altered physical appearance of disabled patients can result in alterations of body image and often such altered body images are much more negative than is warranted by the reality of the situation. Helping patients to maintain an appropriate reality base regarding their own physical appearance is an important intervention which rehabilitation staff can make in the area of sexual functioning.

Facilitating Communication. The ability to facilitate communication regarding sexual issues is central to the practitioner's capacity for effecting attitudinal and behavioral change in patients. Patients must be able to trust that the practitioner will deem their questions appropriate, view their problems as important (but not in any way perverted or "freakish"), and have the knowledge and skills necessary to deal with difficulties once they have been expressed. Because patients often have difficulty asking questions about their sexuality in a direct manner, the practitioner must also be able to listen carefully for subtle verbal cues that the patient has sexual concerns. For example, patients may frequently make reference to "my nature," "my manhood," or "my wifely duties." Follow-up on such references often reveals a patient quite concerned about a sexual issue but hesitant to discuss it for fear of being thought inappropriate.

While many patients may have sexual concerns, no one wants to be pushed into talking about his or her sex life. Be alert to the fact that patients who are threatened by open discussion of their sexuality will usually resist such efforts by *1)* implying that the practitioner is voyeuristic or perverted for wanting to discuss sex, *2)* denying that problems exist in order to turn off the flow of communication, *3)* pointing the finger at the partner and asserting that it is he or she who has the sexual problem, or *4)* pointing the finger at the disability and claiming that it has removed every possibility for being sexual. In these cases it is best to discontinue direct inquiry regarding sexual topics while remaining open to subtle cues that concerns exist which may be discussed later.

Giving Information and Specific Suggestions. The giving of information about sexuality is made much easier if one has mastered the relevant factual information. The practitioner who has never had a formal course in sexuality can learn a great deal by reading a basic text (see, for example, Francoeur,[5] Hyde,[11] McCary & McCary,[14] and Wolman & Money[23]). Information given to patients can be both general (basic facts, referral to readings) and specific to the particular presenting disorder. In providing specific suggestions regarding sexual alternatives, it is important to emphasize that sex is not synonymous with an erect penis inside a lubricated vagina engaged in robust pelvic thrusts which culminate in ejaculation and (less frequently) female orgasm. Rather, sex should be defined for the patient as the verbal, visual, tactual, and olfactory communication which expresses love and intimacy between two people. Such a definition asserts that everyone can be sexual. In many cases (particularly with male patients) the individual will need to move from a dominant, active, initiating sexual role into one which is of a more passive, receiving nature. Discussion of the patient's reactions to such a role change, and endorsement of the new behaviors as novel and potentially liberating variations on previous sexual expression, can help to ease in the transition.

Particular suggestions which may be of use to both patient and partner involve discussion of alternative sexual positions (i.e., variations on the "missionary" or male superior position) and methods for sexual stimulation other than penis-in-vagina intercourse (i.e., manual genital stimulation, use of vibrators or other sexual gadgets, oral stimulation, use of erotic photographs or literature, use of sex talk and shared fantasy between partners, and use of self-stimulation).[6] It is often the case that sexual interaction requires more preparation for those who are physically disabled than for those who are nondisabled. For individuals with catheters, ostomy bags, or loss of voluntary bowel/bladder function, proper instruction regarding procedures that must be undertaken before engaging in intercourse is essential. It is often helpful to include the partner in the discussion, as well as the actual conduct, of such procedures (for an excellent reference on this topic, see Mooney, Cole, & Chilgren[18]).

When to Refer to a Specialist

When permission, information, communication, and specific suggestions for sexual alternatives are not sufficient to alleviate problems, referral to a specialist may be appropriate. In most cases of physical disability, physicians specializing in physical medicine have already been involved in both assessment and treatment of the patient. Some specific sexual problems should be further referred for initial evaluation by a gynecologist or urologist. These include arousal disorders (inability to achieve/maintain erection in the male, inability to attain sufficient vaginal lubrication in the female), disorders affecting orgasm and ejaculation, and intercourse which is painful to either partner. In addition, there are many instances in which referral to a sex therapist is appropriate, even when the major contributing factor to the dysfunction is known to be organic. Sexual difficulties with organic etiologies frequently have psychological ramifications that ultimately affect behavior. Psychological adjustment difficulties particularly likely to occur in patients with a physical disability include development of a negative body image, loss of self-esteem, and fear of intimacy. Relationship problems can also occur when one member of a couple becomes physically disabled. These problems often revolve around anger, on the part of both partners, and guilt over being angry, on the part of the non-disabled partner. Any sex therapist to whom referrals are made should be a licensed health care professional who has received specialty training in human sexuality. Certification from the American Association of Sex Educators, Counselors, and Therapists (AASECT)* is also desirable. Appropriate referral sources can be found in the National Registry of Health Care Providers or through AASECT. It is also useful when making an initial referral to ask another respected professional to make a recommendation. Follow-up on such cases often provides valuable information for making future referrals.

Summary

The rehabilitation practitioner is in a unique position to provide desperately needed sexual counseling and education to patients with physical disabilities. Because sexual problems are almost invariably physical *and* psychological in origin, they should be assessed and treated with both of these contributing factors in mind. The rehabilitation practitioner can serve to facilitate communication regarding the patient's present (and future) sexual functioning by expressing an open attitude and treating the subject with as much frankness as he/she would any other bodily function.

With a minimum of basic education, the rehabilitation practitioner can provide adequate limited information and specific suggestions for alternatives to traditional forms of sexual expression. By conveying an attitude that people with physical disabilities have both the right and the ability to be sexual, the practitioner can give much needed encouragement to the patient. In many cases, the above treatments will alleviate sexual problems and referral to a specialist for intensive therapy will be unnecessary.

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REHABILITATION

perspectives

Sensitivity of One Person to Another

TAMARA DEMBO, Ph.D.

Summary

Disparate perceptions of rehabilitation professionals' behavior by parents of children with disabilities often cause the parents to feel they are treated insensitively. Differences in the counselor's and parents' position toward the child, the purpose of the first visit, and the expectations for the child's improvement contribute to the parents' disappointment. Parents look for hope while the practitioner focuses on reality. The "outsider" position and values of the professional conflict with the "insider" position and values of the parents.

It is possible to diminish these problems if parents are prepared for professional opinions contrary to their own, if professionals have sufficient knowledge when they propose either a realistic or hopeful approach, and if student counselors are exposed to "outsider" and "insider" viewpoints.

Rehabilitation Literature, August, 1964—*Tamara Dembo, Ph.D., was a professor of psychology at Clark University, Worcester, Mass., and director of the University's Research Training Program in Psychology of Rehabilitation.*

WHY DO PARENTS of handicapped children feel that professional people are frequently insensitive to their needs? This question will be discussed first and then suggestions will be made on how we might improve the relationship between professional people and these parents.

Only one frequently occurring case of unsatisfactory interaction of professional people and clients will be discussed here. Much of what will be pointed out, however, will be applicable to a number of other situations.

The case to be considered is the conduct of a professional person toward a client—a parent of a young, extremely handicapped child. The professional might be, for example, a physician, social worker, or psychologist. It frequently happens that, on the first visit of the family to the hospital, the professional person suggests institutionalization of the child. He gives as reasons the inability of the child to improve under any circumstances and the fact that the instituionalization will be best for the whole family. Such behavior by a professional person, during a first visit by the client, is much criticized by parents.

In the following, for brevity's sake, professional people will be referred to simply as professionals.

Social sensitivity or lack of it is frequently considered a characteristic of the personality. It seems to me, however, that the so-called insensitivity of the professional, as it is perceived by the client, is strongly influenced by a number of psychological determinants and by a discrepancy existing between the professional and the client in regard to these determinants. One such determinant is the *position* occupied by the professional in regard to the handicapped child. As we shall see, it is quite different from the position of the client. Another determinant is the *purpose of the visit,* differently thought of by the professional and the client. A third is the difference in evaluation of expectations concerning the *likelihood of improvement* of the handicap.

As a consequence of all these differences, the client and the professional arrive at different requirements concerning the proper behavior of a professional. If, then, the professional does not behave in accordance with the client's requirements, the parent will feel that the professional is insensitive to the client's needs, wishes, and values.

Starting with discussion of the difference in *position* occupied by the client and that of the professional, we shall first describe the position of the professional. The professional himself does not experience the problems brought about by the handicap, that is, the professional is not the sufferer. It is one thing to know that *another person* has a handicapped child and quite another thing to be a *parent* of a handicapped child. Characteristically, the professional is in the position of an outsider, and as an outsider he looks at the relationship of the parent to the handicapped child from a distance. The parent is in quite a different position—he is inside the area or situation directly affected by the impact of the handicap.

The two positions of the outsider and of the insider carry with them two different roles. The role of the outsider is that of an observer, and the role of the insider is that of a participant. Carriers of a role usually carry a notion of an ideal role. The ideal of an observer is to be an objective observer, and he is supported in carrying this ideal by being taught to be objective.

To be an objective observer means to not get personally involved in what is observed. The observer feels that to be a *good* objective observer he should not be swayed or influenced by the feelings of the insider. It is, then, understandable that the outsider may actually avoid finding out how it feels to be an insider. Applying the above to our case, not only is the professional by virtue of his position an objective observer but his values concerning the ideal role make him resist paying attention to the parent's feelings toward the child.

Further, because the observer is an outsider, the impact of the situation in its immediacy affects him little. He is freer to concern himself with more general aspects of the situation and more remote problems than is the parent. In actuality, this is what he does, but he does it in a somewhat abstract way. Not experiencing, as does the parent, the strong ties to the handicapped child in the immediate present, the professional is able to disregard them and emphasize the interests of the whole family. However, being an outsider to the family in question, he does not take the individuality of this particular family into account, and he thinks in abstract terms about what he regards as good for families in general.

For the insider the "here and now" is of great concern, and he has a particular, individual relationship to each member of the family. The parent feels, therefore, that the child who needs more thought, attention, and care than others should get it and that other members of the family can be asked to offer their help. We notice that the values of the insider and outsider are considerably different.

The difference in the positions of the insider and of the outsider, that is, of the sufferer and the observer, influences their judgment as to the *purpose* of the visit. Specifically, the professional sees the purpose of the visit as an objective, realistic evaluation of the situation, as a determination of *facts*, that is, as a determination of the severity of the handicap and of the most probable outcome in the future. If he knew how to alleviate the handicap he would concern himself with the treatment of the child and discuss with the parents how to handle and help the child. In a case that the professional considers "hopeless," he feels he does not have any useful suggestions to make concerning the actual treatment of the child and does not need to pay attention to the problem of dealing with the child day by day. Characteristically, when the parent says that the child has shown some improvement in the past, the professional tends to disregard the remarks, judging the improvements to be either figments of the parent's imagination or so insignificant as not to be worthy of attention.

Turning again to the parent, we find that he agrees with the professional that it is important to have an objective, realistic evaluation of the situation, that is, to know how severe the handicap is and to know what to expect in the future. However, the factual determination is only one of two purposes leading him to go to the professional. The second—and it seems to be the major purpose—is to achieve satisfaction of his wishes. The parent's wishes are to find out that the handicap is not as severe as it looks, that the future entails promise, that there are ways of alleviating the handicap, and that the professional will show him such ways or direct him to somebody who will be able to show them to him. These wishes of the parent are much stronger than his need to know the realistic facts, especially so if the statement of the facts would bring nothing but disappointment. The major purpose of the visit for the parent is to acquire support in his belief in the possibility of improvement rather than to arrive at the knowledge of the certainty of a negative outcome.

These subjective demands of the parent are evaluated by the professional as hindrances to the management of the case. Faced with a "hopeless" case, the professional feels that it is his duty to tell the parent what the actual objective "truth" of the matter is. He feels he helps the parent when he tries to make him become realistic and accept the objective state of affairs. The professional, in what he believes to be attempts to help, might go so far as to pound into the parent that the wishes the parent has are useless and plainly harmful for planning. It is here that the professional and the client part, and it is here that clashes occur.

A client will feel that a professional is "insensitive" if he does not respect his wishes and does not even *try* to find a way to satisy them. The professional will, at the same time, call the client "completely unrealistic" and offer the following argument: If a negative outcome is expected with as high a probability, say, as in 99.9 percent of cases, this is the outcome one has to expect will actually occur. Thus, it is most realistic, says the professional, to count on no improvement and be guided in one's actions by the belief that no improvement will take place. The professional further asserts that such a realistic conclusion not only is valid for him but has universal validity and thus has to be accepted by the parent as a guide in his actions.

The parent disagrees. His paramount desire is to be able to hope for the improvement of *his* child, and this leads him to interpret facts differently. He asserts that the professional should not consider the most highly probable outcome as the one that *will* occur. The existence of a fraction of a percent of probability of the positive outcome (disregarded by the professional) is of major importance to the client. To him this indicates that one out of a thousand cases, or even one out of a million, must improve and that this one child can be *his* child. When the professional says that there is "not even one chance in a million," the parent struggles for hope by asserting that errors in judgment, even by an expert, occur, that there are always exceptions to the rule, and that the professional might have been at fault in placing his child within the hopeless group. Further, there are chances that future discoveries will help the child. The parent demands, therefore, that the professional mention these possibilities to the parent and that he support the parent in his belief that no prediction of a negative outcome can be made with absolute certainty.

The struggle for hope just described is not limited to parents of severely handicapped children. Whenever a person suffers from a threatening loss of greatest importance to him, he struggles for hope. In a situation of despair a person, to succeed in gaining hope, tries and usually is able to make a step that he would usually reject; he exchanges the dictum of probability, which guides us in everyday life, for the dictum of possibility.

The probability dictum prescribes: Be guided by the expectation of the most probable outcome since it is most reasonable to believe that the most probable outcome *will* take place. It is paradoxical that a high probability of an outcome leads us to the belief that this outcome actually will occur. This belief might be supported by the requirement of unilateral guidance needed for orderly planning in life.

The dictum of possibility, which in hopeless situations the person actively attempts to accept as a guide, says: Be guided in your actions and planning by the wished for possible occurrence. One can arrive at this dictum by thinking in the following way. There is always a possibility that the negative evaluation of a situation is wrong; the future is never completely known; therefore, the positive outcome is actually possible: It *does* occur. Since it *must* sometimes occur, it might occur here and now, and it might occur to me; thus the hopeless situation is actually not a completely hopeless one.

In an everyday life situation, when we think about matters of relatively little importance to us, we are supposed to think "rationally." Actually, however, we ascribe to the most probable outcome an irrational certainty of outcome. When we face a loss of value highly important to us emotionally, we seem to become more accurate in our judgment or, if you wish, actually more "rational" in that we do not disregard an outcome of a minute probability of occurrence. The irrationality appears in the greater weight we have to give to the highly improbable, just possible, rather than to the most probable in order to acquire hope.

This ascription of great weight to the merely possible is brought about by emotional means, namely, by the impact of the paramount, all-inclusive desire. How this desire overcomes the weight of the impact of the most probable outcome upon our thinking is not yet well known. Doing away with the weight of the high frequency of the most probable occurrence and the acceptance of the dictum of possibility as a guide in thinking and planning is what is experienced by us as *having gained hope* in a desperately hopeless situation.

The parent, struggling for hope, demands that the professional accept the legitimacy of this struggle. The need for acceptance and understanding on the part of the professional is of paramount importance to the parent.

Here, if only in passing, let us mention that the client needs hope, not only to diminish his suffering, but also to be able to take care of his handicapped child and to engage, without undue strain, in other everyday activities. It is hope that saves him from paralyzing despair and depression. The content of this hope is that the child will improve; the parent does not demand support of the hope of complete recovery.

When professionals who strongly believe in an objective, realistic approach are faced with the statement that many clients object to being robbed of hope, they may give you one of two answers. Some professionals will deny that they rob the parents of hope and say that they only point out to the parents that no improvement can be expected. This, of course, means that, although they see the case as a "hopeless" one, they say they do not touch on the problem of hope as such. There are other professionals who are more extreme in their assertion of the value of a realistic approach; they insist that hope *should* be taken away from the parents because they believe that, if hope is left, the parents will only unduly postpone the most important decision they have to make, namely, whether to institutionalize the child. These professionals insist that the parents should give up hope because this would save the parents from unnecessary trouble such as undue expenses and running from one expert to another.

The latter reasons presented to the parent are judged by the parent to be inappropriate and to show complete lack of understanding by the professional of the parent's needs. The parent made the appointment with the professional to get help with the child. The parent did not come to the professional to ask for advice on how to spend his money or for advice on how to manage his life in general.

From the parent's point of view, it is the professional who lacks in understanding the needs and feelings of the parent and who lacks in sensitivity in regard to social relationships. The parent feels this most strongly when, *unasked*, the professional raises the question of institutionalization. Such behavior on the part of the professional, the parent states, is both painful and shocking to him. Such behavior further implies to the parent lack of respect for his judgment as a parent and an undue attempt on the part of the professional to dominate him. Furthermore, the remarks of the professional that indicate a devaluative attitude toward the handicapped child cause further pain for the client. This is implied when the professional calls the child a hopeless case, not worthy of any effort, just a "vegetable," not a child. The parent feels not only that the lack of respect is expressed to the loved child, for whom the client suffers, but also that disrespect is shown toward him, the parent, who so strongly relates himself to a devalued being.

All of us might agree by now with the parent that the professional, at least the one who goes to the extreme in his realistic and objective evaluations, shows lack of sensitivity in regard to the most *complex* relationship of the parent to his handicapped child, full of meaning to the parent, full of negative but also positive feeling toward the child. This relationship requires slow working through and disentanglement before suggestions, if any at all, concerning the institutionalization of the child can profitably be made to the parent by a professional.

In the beginning of this presentation the question was asked: Why do parents frequently feel that professional people are insensitive to their needs? A brief, inclusive answer can now be given: The professionals frequently appear to be insensitive to the parents because the professionals' position and values as outsiders stand in opposition to the position and values of the parents as insiders.

And now as to the second question: How can the relationship between professional people and clients be improved? To answer this question we have to take a stand toward the views of the professional and the parent. This is necessary because the parent's and the professional's dissatisfaction with each other does not stem primarily from the way in which the two parties communicate with each other, but rather from a basic disagreement in their evaluation of each other's values. The main difficulty lies not in the form of the communication between the professional and the parent but in the content of the communication.

In order to make suggestions that would promise to alleviate the severity of the disagreement between the two parties, a third party will have to take a stand as to the viewpoints of the two parties. There are several ways of taking a stand: One can take sides with one or the other party, or in part with both of them, or one can take no sides.

When we act as researchers investigating the relationship of the professional and client and try to suggest an improvement in this relationship, we are the third party. As investigators we have to take the stand that science permits us to take, namely, the one that can be shown scientifically to be valid. However, actual knowledge concerning the effect of the "realistic" or the "hopeful" approach upon the child, parents, and siblings—knowledge that would permit comparisons—does not exist. Nor is knowledge available as to the effect institutionalization or home care has on a severely handicapped child and on the members of the family. Thus, let us admit and state bravely that we do not know whether, when, and under what circumstances the viewpoint of the professional or of the parent is to be recommended. It is a fact that as scientists or researchers, as experts in knowledge, we have at present no scientific basis for stating to the parent what approach to take.

Does this mean that we are doomed to passivity? In no way. We can make suggestions as to what we believe will lead to better relationships between professionals and parents.

Here are three sets of suggestions for consideration. One set concerns the parent, the second professionals presently in practice, and the third students training to become professionals.

Let us consider the suggestions concerning the parents first. The discord between the parents and the professionals would be diminished if the parents were prepared to expect professionals to make recommendations and to express opinions contrary to their own. Also, the parents could be informed in advance that the professionals frequently do not support hope as to a positive outcome in the future, nor do they pay attention to parents' remarks as to the recent improvements of the child. The parents could be shown how the position of the outsider leads the professional to a particular viewpoint as to the purpose of the visit and makes him evaluate most highly the most probable outcome. The parents could be informed that the question of whether their or the professionals' approach is better for all involved has not yet been adequately studied and that knowledge in this area is lacking. The attention of the parents could be drawn to the fact that the suggestions of the professionals in this respect sometimes may not be better than those of any other person.

If the parents are brought to the realization of all of this, one should expect that they would, as the saying goes, understand better "the position of the professional" and be less disturbed by the unwelcomed recommendations of the professionals. The parents' first visit to the professional is a particularly appropriate occasion for the communication of the above information.

To the professional in practice it is suggested that he himself take into account the following points when talking to parents: First, knowledge sufficient to decide whether a so-called realistic or hopeful approach is better is not available. Second, his own views on the matter are determined by his position, his expectations, and his personal values, just as those of the parents are due to their position and their values and expectations. Third, parents come to him for comfort and support of hope and he can alleviate, at least momentarily, the suffering of the parents by supporting hope. Fourth, even before starting to examine the child, he might inform the parents about the suggestions for the parents that were presented above. The professional might then, if he wishes, state his personal opinions by designating them as his *personal* leanings toward a realistic or hopeful approach.

In offering a set of suggestions for students in professional training, we can go further than those we give to an established professional person. At present the development of viewpoints, opinions, and selection of values to be used by students in contacts with clients is left to the natural course of events, that is, it is left to the pressure of the position that the students will occupy as professionals and to their personal preferences. Therefore, when students become professionals, they frequently act without realizing the one-sidedness of their viewpoints.

A one-sided viewpoint is characterized by a lack of realization that there are possible advantages to be gained from taking the point of view of another person. When a student adheres to his own outsider's viewpoint, he, of course, realizes the existence of the parent's hopeful one. However, he sees this other viewpoint from his own position, that of an outsider, and therefore as having only disadvantages and as leading to difficulties. He actually does not understand what makes the other person believe in the advantages of his own viewpoint. He can, however, be taught to see with the eyes of the other and to see the advantages of the viewpoint to which the other adheres. This can be done by showing him how to take the position of the other, by teaching him about the conditions leading to the other's viewpoint, and by making him accept tentatively some values of the other as premises.

Through such teaching, the viewpoint of the other would appear to be quite meaningful and have some value. The understanding of both viewpoints, one would expect, would lead to a respect for both viewpoints. Briefly stated, the actual understanding of the other, which involves a tentative acceptance of premises and values of the other, should make the student "emotionally tolerant."

Let us add that, if the professional and the parent had the occasion, at least temporarily, to take the viewpoint of each other, neither would feel prompted to accuse the other in an emotional way; the professional would not find the parent quite so "unreasonable" and the parent might not find the professional so "insensitive."

The temporary taking of the position of the other might not only lead to emotional tolerance but also might bring about an even more far-reaching change. It might lead to the reconsideration of one's own viewpoint and to a change in one's beliefs and actions. Whether the outsider or the insider could change more easily is a question for research on value problems. It is, however, only one of the many topics in the area of value research that are in need of investigation if one intends to achieve better understanding between professional people and their clients.

The above discussion has dealt with one serious difficulty between the professional and the parent. Of course, it is not the only one. To mention some others, let us point to the cases in which parents come with a request for a "valuable treatment" that the professional might consider inappropriate. For example, they might virtually insist on the necessity of early bracing of a child, having heard from someone that this is a promising treatment. If the professional feels bracing inadvisable, he legitimately will have to act against these "hopes" of the parent. In this article we have not asserted a necessity for the professional to support all the hopes of the parent but asserted only the necessity of supporting a general psychologically hopeful atmosphere, that is, a hopeful view of the future, a belief in the possibility of improvement that offers to the parents a way of coping with the immediate demands of living with the handicapped child and the gradual acceptance of the particular situation.

It may have seemed that in this article we have sided too much with the parents and that the problems facing the professionals have been slighted. The unwarranted demands of the parents, the professionals' feeling of helplessness in hopeless cases, the necessity of conveying disappointing news to the parents, robbing them of exaggerated hopes, and, last but not least, the difficulties in guiding the parents who resist warranted advice are, of course, important concerns of professionals and they are problems requiring thorough consideration within professional-client relationships. Taking the point of view of the other, on the part of both professionals and parents, necessitates thorough knowledge of both viewpoints.

In conclusion, the problem of how to arrive at the most fruitful relationship between professionals and clients is not limited to the professional and the parent of the physically handicapped child but exists in all professional-client relationships. In fact, the problem of insensitivity of one person to another is present whenever an outsider and insider meet.

Sexuality in the Handicapped: Some Observations on Human Needs and Attitudes

GIOVANNA NIGRO

Summary

Parents, families, and rehabilitation professionals often overlook or deny the sexual nature of people with disabilities. These attitudes are seemingly related to values that equate physical beauty with sex and romance. Sex education is essential to overcome these prejudices. Parents need guidance to answer their children's questions and help them achieve appropriate sexual identity. Special education students require knowledge about functions and feelings.

Parents and professionals must confront their anti-marriage sentiments toward people who have disabilities. They must recognize that once people are educated about their own sexuality and the responsibilities of an intimate relationship, they must be free to make sexual and marital choices.

Rehabilitation Literature, July, 1975—*Giovanna Nigro was director of recreation and adult activities, United Cerebral Palsy of New York City, and consultant in adult programming for United Cerebral Palsy Associations.*

I WOULD like to announce at the outset of my talk that I am not an authority on sexuality in the handicapped. I have no medical or scientific material to present to you. However, I have worked with physically handicapped teens and adults for many years, and I can offer you some observations that may be useful.

I will restrict my comments to a discussion of sexuality in the lives of people who are lifelong handicapped and state simply that the problems of those who become handicapped in adulthood, after sex patterns and relationships have been established, are quite different and require different considerations and solutions.

The lifelong handicapped can be divided into three general categories. Some handicapped people such as the spinal cord-injured, may have, as a result of their disability, an impairment in sexual functioning. Others, such as the cerebral palsied, as far as we know, are not disabled in this area. Still others may have mental deficiency in addition to their physical handicap, which is usually not related to any impairment in sexual functioning. Each of these groups has quite different problems to face in dealing with sex. However, all three categories are composed of people who have *sexual needs* and are *sexual beings* in spite of their sexual functioning or their physical handicap. In addition, all three groups share a problem common to all handicapped people, which is the *attitude* of nonhandicapped people with regard to their sexuality. Unfortunately, not only the general public, but even many professional people working with the handicapped, and certainly the parents and families of the handicapped, frequently overlook or deny the sexual nature of the handicapped, an aspect of living that is the birthright of all people, regardless of their physical condition.

Public attitude that attributes asexual natures to the handicapped seems to be related to cultural values equating physical attractiveness and beauty to sex and romance. This attitude prevails to such an extent that some people find the very thought of an interest in sex among the handicapped an indication of perversion. Our society's preoccupation with outward appearance certainly compounds the problems of the handicapped, not only with regard to other people's acceptance of them in every respect, not the least of which is in the area of sexuality. It also makes the usual problems of adolescence more pronounced, so that the handicapped youngster has to cope with not just the concern about acne, or being too fat or too thin, or the wrong color hair, and so on. He or she also has to come to terms with a distorted body, a withered limb, an ugly brace, or a wheelchair cage.

Some justification for the attitude of professionals who "overlook" the sexual needs of the handicapped may be made in connection with the fact that they are so preoccupied with treating the handicapping condition that they lose sight of a concern for other aspects of the person's life. However, in this age of concern for the "whole person" in patient care, this argument cannot be upheld. It is more likely that professionals dodge the sex issue because it is so complex and because of their own hang-ups and inability to address themselves to helping their patients in the area of sexuality.

The parents of the handicapped, those poor beleaguered souls who bear such a heavy burden in every respect, have perhaps the best excuse for "overlooking" their child's sexual nature. For parents of the able-bodied, the need to recognize and acknowledge their child's interest in sex, and a growing awareness that their child is moving into a life including sexual relationships and sexual activity, though perhaps difficult, is unavoidable. The parents of a handicapped child, however, may be dealing with a dependent person whose relationship to the parents continues to be childlike in many respects, whose time and activities are more likely to continue to be family-centered, whose peer relationships are limited, and whose lack of privacy and physical restriction limit his experimentation with both social relationships and sexual activity. Indeed, many parents of handicapped children never acknowledge their potential adulthood (and eventually their actual adulthood), so it is not hard to understand their reluctance to perceive sexual needs or their inability to prepare themselves and their child for a healthy, happy, sexual future.

All the foregoing is an indication that sex education, in the broadest sense of the word *education*, is essential for all of us, parents, professionals, and the handicapped themselves. For the parents, the initial lessons ought to be concerned with helping their child achieve an appropriate sexual identity, from his or her earliest days. So many of the adults we see are almost "sexual neuters." Their physical handicap has assumed so important a place in their lives that they have little awareness of themselves as boys and girls, men and women. I might say that this seems to be less of a problem with the teens and young adults that I see, than with older adults. However, it is extremely important, and I make mention of it here so that you might emphasize it in your dealings with parents. It is particularly important, perhaps, with severely handicapped boys, whose physical dependence often prevents them from acquiring a masculine self-image and a male orientation. (Perhaps I should not be singling out boys in this era of women's lib and role reversals.) But sexuality is so important to total personality development, and handicapped children ought to be brought up to have a full appreciation of themselves as men and as women in the society in which they live.

Parents of the handicapped, as well as all parents, ought to be educated to treat their child's questions and exploration of his body and curiosity about other people's bodies as opportunities for helping him learn to have as healthy and complete an orientation to his own sexuality, and to human sexuality in general, as is possible within their capacity of handling this area of his education.

The public schools, where sex education is becoming a commonplace part of the curriculum, must be encouraged to include this subject in classes for the handicapped. Too often, special education classes have concentrated on basic academic material, even to the exclusion of such subjects as music and art and physical education. Let's see to it that the handicapped children are not also excluded from sex education courses. And let's recognize that this subject perhaps has more justification for an even stronger emphasis in classes for the handicapped, because handicapped children, due to the limitations on their lives imposed by their own restricted mobility and therefore diminished social outlets, have less opportunity for acquiring this knowledge through self-initiated or peer-initiated activities.

This leads us to the most important, and most debated, area of this discussion—real sexual activity, including dating and courtship and, for some, marriage and family planning. For many mildly handicapped people, the whole business of meeting and mating and marrying may be no different than it is for able-bodied people. There is one important difference, however, which should be noted. Handicapped teenagers and young adults are subject to the same cultural influences that we all are. For the most part, they expect, and desire, to meet and fall in love with beautiful girls or handsome men, not handicapped, who fit their image of the idealized sex object. Some achieve this dream. Others are faced with the agonies of "settling for" something less ideal, perhaps another mildly handicapped person. But the mildly physically handicapped, habilitated, self-supporting person, can make his way and find a suitable mate with whom he can establish a home and make family plans that suit himself and his mate. Public opinion and family opposition notwithstanding, he can be the master of his own fate. If his physical disability is one related to genetics, then counseling about family planning is certainly in order. If not, then he and his mate can make plans that suit their circumstances.

The more physically disabled and retarded face other kinds of obstacles. Parents frequently object for an infinite number of reasons, some of which would exist even if their child were not handicapped. But the handicapped adolescent or young adult who is still dependent on his parents physically and financially cannot defy them and go ahead on his own as his able-bodied contemporary might do.

The moderately to severely handicapped young person might look to us for assistance in helping to convince his parents that he has a right to, initially, an opportunity to establish romantic alliances with other young people (usually handicapped also, since those are usually the only people he gets to know and spend time with away from his family). And he does have this right, I hope you'll agree. Parents' objections to their handicapped children's dating (and probably our own objections as well) usually have to do with the fact that the young adult "child" will only be hurt in the long run, because where can a romance lead to but an eventual breakup and heartbreak. Certainly it can't lead to marriage. Or can it?

And this is the real crux of the matter. Who has the right to marry, and who sits as judge to make such decisions? Who decided whether you should marry and whether you would make an adequate parent?

I would first like to say that relationships between two people that don't necessarily lead to marriage can provide enough pleasure to offset the pain of the eventual demise of the relationship. So there is some justification for establishing such relationships at all. Furthermore, many long-term alliances or engagements that I have witnessed have given the couples involved, who feel that they could not manage marital life, a semblance of normalcy and many years of satisfaction and emotional fulfillment. Also, of course, not all handicapped people want to marry or find suitable mates, just as is true for able-bodied people. Certainly, I am not advocating that all handicapped people should marry.

But let's examine what marriage is all about. To begin with, sex is one part of marriage, and a very important part. No question about that. However, marriage is far more a way of fulfilling emotional needs. And the right to establish a meaningful intimate relationship with another human being can be the difference between a solitary empty life and a rich sharing partnership between two people, which can make the lives of both of them so much more rewarding. Does anyone have the right to deny this experience to the handicapped, who already have been denied so many other accepted routine experiences that most of us take for granted?

In fact, marriage can be a very satisfying way of life for handicapped people who are too disabled to participate in other human endeavors that most able-bodied people use to give meaning to their lives, mainly their work. Some of the couples I know, before marriage, were dependent or semidependent on their families, felt useless, were isolated, and, in general, were living life in a very marginal way. In their marriage, they have found a meaning and a purpose far beyond that which marriage holds for the average person. And because the marriage is so central to their existence, frequently it is a much stronger, more binding union than we usually see.

One couple I know, both quite handicapped but very resourceful and far from helpless, keep house together, shop for groceries, prepare their food—all, I might add, without regard for the usual male-female roles. They do all this at a snail's pace, because they are so handicapped, and it consumes their day. They take care of each other, share their chores, and when they are finished they relax and make love. What could be more beautiful?

Making love is, for handicapped people as for others, a very private and uniquely worked out practice. If their disability is such that they can engage in sex in the standard or conventional way, they have no more problems than able-bodied people in working toward a good sexual adjustment. If their physical disability prevents them from the usual practices, either because of physical distortions or because of impairment in sexual function, this need not be a barrier to achieving sexual satisfaction. Our book stores and libraries are filled with manuals detailing an infinite variety of methods of achieving sexual pleasure and telling us repeatedly that no practice acceptable to the two parties involved ought to be overlooked. In addition, there is a growing body of literature that rather explicitly describes the methods disabled people with sexual dysfunction have found for achieving success in finding and giving sexual satisfaction. I don't want to imply that no serious problems in this area may arise, but it is apparent that a loving, determined, and resourceful couple, regardless of their handicap, can find an acceptable way of fulfilling their sexual needs.

Some of the objections to marriage between handicapped people have to do with their inability to support themselves and their inability to bear and raise children responsibly. With regard to financial support, most handicapped people who cannot support themselves are entitled to public assistance. This is true whether they marry or not. And simple arithmetic will prove that it is cheaper to support two people in one apartment than two people in two apartments (and certainly less than two people in a chronic hospital or nursing home). Aside from the simple facts stated here, consider the fact that many people whose circumstances have nothing to do with physical disability are being supported by public assistance. Can we honestly deny marriage to physically handicapped people because they are not self-supporting?

The question of bearing and raising children is perhaps even simpler to deal with. The handicapped couples I know have given, to a large extent, more thought to this question than the average couple has. Their realization of what they can honestly and realistically accomplish and be responsible for has been much more carefully analyzed. Their decision to have children or not to have children has usually been made in relation to the total soul-searching self-examination they have put themselves through in making a decision about whether they could function in a marriage together. Those whose disability is related to heredity have had the best possible professional advice and are acting in accordance with the facts as they perceive them. Most of the couples I know have felt that the most they could expect to accomplish was mutual self-care and that children were out of the question. Even where the desire for children is strong, they have made the decision to establish strong ties to the children of relatives and friends and be satisfied with that.

One couple I know is raising a family. They have two very young children and are managing quite nicely now. They realize they may need help when the children are more active, and they are responsibly planning for the future. But they are loving parents, and their children are healthy and happy.

One young woman I've known for a long time, who had a stormy relationship with her own rejecting mother all of her life, married and had a baby. She had expected that she and her husband would be able to take care of the baby, since the husband was not so disabled. However, the marriage didn't last. The baby was placed in a foster home and is doing well. The mother sees her child regularly, and the child knows she is her mother. Having borne this healthy child (which is something her own mother was not able to accomplish) is probably the single most important achievement in this young woman's life, and she has attained a kind of peace with herself and a purpose for existence she never had before. Sick, you say? Perhaps, but how many other sick reasons have you heard for people bearing children?

Another couple I know had a baby who, by prearrangement, was to be raised by the childless sister of the wife. They have a beautiful daughter who knows them as aunt and uncle. The child is happy with the parents she knows as her own, and the handicapped couple take great pride in the addition that they have made to their extended family.

I know some mildly retarded couples who are raising happy healthy children. Their children are no worse off than the hundreds of thousands of children born to families of marginal people, not designated retarded, whose limitations are known to us all and who are sometimes classified as "culturally deprived." The children of these retarded couples are, in fact, better off by far, for the retarded parents know they have deficiencies and know they must avail themselves of professional advice.

At any rate, there is not a simple solution to the question of whether a handicapped couple, retarded or not, should be restricted in their right to parenthood. Again, who makes the decisions for the rest of us?

In summary, handicapped people are sexual beings. Parents and professionals and the public have no recourse but to accept that fact. With this established, we have an obligation to help them develop appropriate sexual identities, educate them to understand their own sexuality, arm them with information about being responsible human beings, and then allow them to make their own way in life.

The Ideal Human Service for a Societally Devalued Group

WOLF WOLFENSBERGER, Ph.D.

Summary

In satiric tones reminiscent of Swift's "A Modest Proposal," the author excoriates social service workers and agencies for their all-too-common ill-conceived, insensitive, and ineffective plans, programs, and facilities. Each painful example indicts traditional rehabilitation policy while implying how it can be changed. The concluding questions, asked in mock incredulity, have already been answered.

IT IS SAID that, by observing an interrelated set of phenomena, one can infer its dynamics and assumptions. Having observed thousands of service settings in extremely diverse areas (mental retardation, mental health, aging, physical and sensory impairment, corrections, and educational, habilitational, residential, counseling, assessment, etc., services), I am now prepared to describe what obviously must be the ideal service setting as conceptualized by human service planners and practitioners. This ideal is inferred from almost universally recurring attempts to achieve certain conditions, especially as ascertained during the application of the Program Analysis of Service Systems (PASS)[1,2] to approximately 400 diverse human services.

First, you must collect as many devalued people as possible in one place, people whom you have first "evaluated." They should then be segregated in as many ways as possible: the service should be in an isolated spot, with poor transportation, and, especially if the people have difficulty in walking, there should be no sidewalks. (For one outstanding example, we cite Het Dorp, a community in The Netherlands that was located and constructed, purpose-built specifically for handicapped persons. It was on the only hilly terrain in the entire country, so that, at any one time, over half the electric wheelchairs of the residents are under repair.)

People in wheelchairs, we bring to our service in an ambulance taxi called the Tender Loving Care (TLC) Service (minimum charge is $25 per round trip). The other cab company we use has vehicles that have foot-high letters on the rear doors saying, "CAUTION—WHEELCHAIR PATIENTS," but, when you stop the van to open the doors as passengers board or deboard, the sign is no longer visible. The third component of our ideal transportation service subsystem consists of yellow school buses (for children) by means of which we transport *adults* to sheltered workshops and recreation.

If an inaccessible location is impossible to find—or, better yet, in addition to it, you must find a location that is as close as possible to or on top of a cemetery or garbage dump, and that was formerly a brothel, TB sanitarium, or gay bar. Preferably, too, the location should have been used previously by some other human service to a devalued group, or it should presently be condemned as unfit for human use.

Rehabilitation Literature, January, 1978—*Wolf Wolfensberger, Ph.D., was a professor in the Division of Special Education and Rehabilitation, Syracuse University, Syracuse, N.Y.*

If there is a neighborhood surrounding the program, the program must clash with it. So we should put child development centers in factory districts, workshops into residential areas, and so on. Also, it is essential that the appearance of our facility clash with all the other buildings in the neighborhood. Thus, it must be either the biggest, the oldest, the newest, or the oddest building on the block (e.g., a Saarinen hyperbole on a Victorian street). If you are not the only ultramodern building on a Victorian street, or the only high-rise in a low-rise neighborhood, then at least you must add a bizarre annex to the building, or put up a 10-foot chain link fence, or attach an orange fire escape down the front facade.

Of utmost importance is that your building be cleverly disguised so that it does not in any way look like what actually goes on inside it. So for a sheltered workshop, a church building is a most clever cover; a residence should be in a building looking like a jail or a warehouse; a school program should operate in a building that most people would have mistaken for an ordinary residence. You get the idea, don't you?

Once you have your location and your building worked out, then you should mix devalued client groups, so that the less devalued group gets to look like the more devalued one. For example, you should put together people who are mildly retarded and profoundly retarded, retarded people with people who are emotionally disordered, poor people with drug offenders and with people who have drinking problems, etc.

Relatedly, you should also mix up the age groups, for instance, so that the older group gets to look childish. Putting elderly people and handicapped infants in the same nursing home might do, or special education classes for handicapped teenagers should be placed in an elementary school; severely retarded teenagers, of course, should be placed in a preschool day care center.

Next, you should make the client group so large that it becomes impossible for the surrounding social systems and resources to relate to them in any way, and so large that even you cannot identify or relate to clients as individuals. And when your clients do occasionally go outside the facility, make sure they go in groups that are large enough so that everyone will notice how different they look.

One of the most universal imperatives is to choose a ridiculous and/or stigmatizing program or facility name, perhaps one which has great sentimental meaning to the board of directors: Hope Haven for a custodial service; Madden Zone Center, for a regional center for mentally disordered people; Battey State Hospital, for an institution for the disordered and retarded; Toomey-Abbot Towers for a high-rise for the elderly; Freezer's Personal Care Home, for a nursing home for the aged; Golden Opportunity Convalescent Home for the dying; St. Jude's Hospital (patron saint of hopeless causes) for a hospital for handicapped children; Bahr Treatment Center for an alcoholism clinic; etc.

Then you must go out of your way to find and employ stigmatized and devalued staff. Prime candidates are retired school teachers no longer able to cope with the able-bodied hellions in the regular grades, physicians who don't have licenses, preferably unable to communicate in English, and who, if they are not alcoholic, have wives who are. A great and creative modern favorite is to have prisoners teach scouting to handicapped children, by busing the children to the prisons—preferably with a nonambulatory group of foster grandparents assisting. Isn't it remarkable what prisoners can do with handicapped people, as long as you keep them away from nonhandicapped ones! And as everyone knows, mentally retarded people make excellent workers in nursing homes for other people's decrepit mothers and grandmothers—as long as they don't lay their hands on my old mother or, God forbid, on myself in case I have to go to a general hospital.

If you are a rehabilitation agency, then it is *de rigueur* to hire your own clients as staff, because if you didn't, no one else might. At the very least, you simply must have a few dedicated counter-culture adults who never cut a hair or beard, never comb, never bathe, or clean their fingernails, who dress awful, and smell worse—but boy, are they good with the kids!

Now, as to the program itself, it must operate the fewest possible hours of the day (at most from 9:30 to 2:30, with two breaks and a long lunch); it should operate the fewest possible days of the week (perhaps Monday, Wednesday, and Friday), and for only eight months of the year. To make sure that everyone understands the nature of your program, you should prominently decorate the environment with Mickey Mouse figures and motifs, pictures of clowns, hobos, and circuses, and, especially if dealing with children, you must give animal and vegetable names to the groups and rooms, or the names of fruits. Thus you might have the turtles, the chickens, the ladybugs, the jaybirds, the daisies, the lemons, the bananas, and so on. You might even refer to the group as your little fairies.

Now what else can we call the people whom we serve? That's easy. If they are *not* sick, we call them patients. If they are no longer children, we call them kids. Old ladies we call girls. People who have seizures we call epileptics. Retarded people we call retardates, although we still shy away from calling mentally disordered people disturbates. People who have to use a wheelchair we call wheelchair-persons. There is much status to being a chairperson, even if in a wheelchair.

Should someone prevent us from using such labels, we still have our voice. So when confronted by blind, old, or foreign-born people, we shout. When confronted by distressed people, we whisper. When we talk with old or handicapped people, we raise our voice an octave and chant melodically, e.g.: Good morning, Mrs. Jones, ♫ how are you today? ♫

Your program must also be aimed at people much younger than those you actually serve, or at least look that way. To the old folks in nursing homes you give dolls; to retarded teenagers, you give Dick and Jane books to read; to physically handicapped teenagers you give Montessori equipment designed for two-year-olds, so that they can practice their dexterity. If you run a sheltered workshop, and all else fails, you can manufacture toys, children's calendars, and make sure all the workers carry Snoopy lunch boxes.

When you have accomplished all of this, then you are ready for your advertising and self-glorification campaign. Look how beautiful we are! Look how dedicated our staff! Look how happy our clients are! How high-quality our program! How cost-beneficial our management! Dr. Wolfensberger, how *dare* you question our motives and nobility!

But, ho! What's this? What gives with that rotten, no-good public? Why won't *they* accept the handicapped? Why are *they* prejudiced and rejecting? Why don't *they* hire the handicapped? Why do *they* put up architectural barriers? Why won't *they* fund *us*?*

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*We hope the reader realizes that we did not have to invent a single one of the examples given, and that each of these has been glorified and defended by workers in the field.

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Some Negative Effects on Family Integration of Health and Educational Services for Young Handicapped Children

NANETTE L. DOERNBERG, Ph.D.

Summary

Treatment approaches to children with physical disease usually assume that any effective treatment is usable on the child and beneficial for the family. Clinical experience indicates, however, that these treatment plans focus on the disability rather than on the child and family's well-being. The resulting disruption of the family support system threatens the child's rehabilitation and accentuates family stress.

Several case studies illustrate the intensified guilt and anger resulting from activity focused solely on a child's disability. Many of these treatment "side effects" are avoidable. Family involvement in treatment plans, flexible appointment schedules, regular support care from nonfamily members, coordinated counseling for the whole family, and periodic reassessment will help families avoid serious psychological disabilities.

PREVAILING TREATMENT APPROACHES to young physically handicapped children pose a threat to one of the fundamental tenets of the American Orthopsychiatric Society, namely, that the organic unity of the family is of signal importance. The service delivery system for treatment and therapy to these children seems to be founded on two types of implicit assumptions: First, that habilitation of the child is paramount and, therefore, any efficacious treatment should be used and will be good for the child and, second, that what is good for the child is good for the family.

This results in patterns of service focused on treatment of the child's handicap. It is expected that families will be able to make use of these services in such a way that benefit will accrue to the child and to other family members.

These assumptions seem incontrovertible. Yet, when viewed from the standpoint of my many years of clinical experience working with families of these children, treatment plans based on these assumptions pose risks to family integration. Rarely is an analysis made of potential net losses and gains *to the family* as a result of treatment. Rarely are priorities considered from the whole family's viewpoint. Benefit is defined solely in terms of the amelioration of the handicap.

It is not the assumptions that are faulty. It is the criteria used to define "habilitation of the child" and "good for the child and family." It is not good for the child or family when the focus of treatment is on the handicap instead of on the child's and family's general well-being.

By this narrowing of the concept of treatment, a burdensome, destructive regimen is imposed on family and child that disregards the fundamental importance of healthy family functioning for each member, including, but not exclusively, the handicapped child. When treatment of a specific member of the family fails to take into account additional stresses inherent in the treatment itself that threaten or destroy the family, such treatment may erode the very family support system vital to the child's and family's opportunity to function most normally. The family and the child become pinioned on the handicap.

Rehabilitation Literature, April, 1978—*Nanette L. Doernberg, Ph.D., was associate professor of pediatrics and psychiatry, Albert Einstein College of Medicine, Yeshiva University, New York, N.Y.*

These negative effects of services, and here I am referring only to suitable services, not those that are substandard or inappropriate, are superimposed on the stresses already existing in the family of any young child with a significant handicap; the difficulties of daily care, as well as the pain, anger, guilt, sadness, frustration, and helplessness that are indigenous to all such families.

The Joint Commission on the Mental Health of Children (*Crisis in Child Mental Health: Challenge for the 1970's; Report*, New York: Harper & Row, 1970) states:

> Any commitment to children is a commitment to the family unit. . . . We must not lose sight of the fact that any service, or lack of service, which affects one member of the family affects all members, brothers and sisters as well as parents.

It is my thesis that clinicians who work with handicapped children do lose sight of this continually or give it mere lip-service. Their message to the family, usually the mother, is that, to be considered a good parent, she should be available to implement all services for her handicapped child. At the same time, she and society expect her to attend to the needs of her other children, her mate, and herself. Since this is impossible, she is double-bound. The marital relationship, the mother's interactions with her other children, the father's relationship with his handicapped and normal children, and the siblings' relationships with each other are all distorted.

The vast majority of services for these children directly and extensively involve the child's mother as therapist, teacher, trainer, or, at the least, transporter. If the child is being seen at a specialty clinic, he may be offered physical therapy, bracing, occupational therapy, speech therapy, treatment with medication, and/or surgical intervention. It may be suggested that he participate in a play group, either attached to the clinic or elsewhere. It is not at all uncommon for such a child to have appointments several days a week and for his parents to be expected to follow a supplementary course of therapies at home.

There is little time, money, or energy for the development of normal interpersonal relationships between or among the family members, much less outside of it. This serves to handicap the child even more, since he, as well as his brothers and sisters, is deprived of the opportunity to participate in a normal family life and, therefore, there is no model other than the one of illness from which to construct a personal view of what a family is like.

Case History: Ralph is a 6-year-old boy of average intelligence. He is an attractive, highly verbal, "wise-guy" child whose seizures are controlled by medication. His middle-class family consists of his mother, father, a 4-year-old sister, Susie, and Ralph. He attends a regular school where he is managing academically, has trouble in graphomotor areas, and is somewhat of a behavior problem. He was referred to my service as presenting a management and behavior problem at home, with a goal of helping his parents understand and handle him more comfortably. He was already receiving occupational therapy from the clinic and his mother had been offered social service intervention to help her deal with the household stresses which were contributing to her high blood pressure, frequent depressions, and outbreaks of hysterical rage which were directed against the other members of the family.

The household was chaotic. Ralph and Susie fought constantly and ferociously. Ralph's father alternated between thinking that there was nothing really wrong with his son and thinking that he was seriously handicapped. He was particularly upset by Ralph's clumsiness due to his own intense interest and involvement in sports. He interpreted his son's behavior as being within his control. Since Ralph's handicap was a fairly subtle one, it was particularly difficult for the father to understand its implications. He was never able to take Ralph for treatment because of his own extra heavy work schedule necessitated by holding two jobs to meet the extensive medical bills. Since he was out of the house all day, every day, he was unable to spend any time with Ralph for pleasure.

Mrs. J., a substitute teacher, was frantic. She was trying to maintain five scheduled appointments a week at the clinic, get Ralph to do his exercises at home, explain to Mr. J. why Ralph acted as he did, and why Susie and Ralph fought, and to explain to Susie why she should be nice to Ralph. She also took Ralph to school and back each day and dropped Susie at her playgroup and picked her up each day. When I first met Mrs. J., she was talking about disappearing and never coming back. Mr. J. was either not speaking to her at all or berating her because of what he felt was her failure to deal with Ralph's behavior.

The mother and handicapped child have become a family subunit. Since all appointments must be scheduled between 9:00 a.m. and 5:00 p.m., Monday through Friday, any possibility that the father could share this aspect of the child's experience and also develop some comfort and expertise himself is eliminated. Since the child has special needs that require some training to meet, and since only the mother can be available to get this training, the father is further excluded. To be able to do the treatment or therapy himself, he must be taught the "how" and the "why" by his wife, who is further forced into the uncomfortable and untenable position of again demonstrating to the father that she is, perforce, the household expert on this child. This is particularly malignant because of the already existing stress on the marriage by virtue of the handicapped child. The father, under such circumstances, is really "odd man out," fearful and uncertain as to how to handle his child physically or psychologically, not really as competent as his wife because of his lack of opportunity and training, unsure of his role with this child and as the husband of the mother of this child, angry at her for being in this position and at the clinicians who have indirectly contributed to his demoralization. Even counseling, offered to help the family understand and deal with these dynamics, is almost always offered during the day in a "mothers' group," further enhancing the mother's role in relation to the child and further distancing the father or, again, putting him in the position of learning from his wife, with no expertise on this subject to share with her.

Case History: Janie is a dark-eyed, tall, slim, 6-year-old girl. Current diagnoses include: mixed atypical cerebral palsy with spastic diplegia, mental retardation, expressive language impairment, partial hearing loss, and esotropia. Her seizures are now controlled by medication. She is nonambulatory and wears short leg braces. She is making some limited progress toward ambulation.

Until recently, her behavior also presented major problems. She was tangentially related and displayed many bizarre behaviors, such as echolalia, hand-flapping, perseveration, and almost total lack of eye contact. She screamed when she was not being physically tended by her mother and was unable to occupy herself for even two minutes.

She is currently enrolled in a special class for the multiply handicapped. She is also receiving the following weekly services: occupational therapy, physical therapy, and speech therapy. She and Mrs. L. are also being seen each week for help in home behavior management, and Mrs. L. attends a parent-group oriented toward helping the families cope more comfortably and effectively with the child at home. She is also being fitted for hearing aids.

Janie lives with her mother, father, and 12-year-old brother, John. It is a close, lower middle-class family of Italian background. Both parents were born in the United States. Mr. L. works long hours as a waiter. Mrs. L., in addition to caring for the house, works eight hours a week for an organization for handicapped children as a home visitor to families with mentally retarded children and is an active board member of the organization.

Mrs. L. has sole responsibility for Janie. She alone takes Janie to all her appointments and implements treatment at home. She has become an expert, not only on Janie, but on young handicapped children. Janie's handicap is the focus of her life.

Mrs. L., at age 29, has developed severe back problems from carrying Janie, who has no wheelchair. She has become a competent martyr who complains only in passing and then immediately feels guilty about complaining, being tired, being angry.

Not only is Mr. L. on the periphery, but so is John, the normal sibling. Mrs. L. is deeply aware that her involvement with Janie results in John's not getting enough of her attention. She feels angry about that, as does John, and guilty about the anger, as does John. If she spends more time with John, she is unable to keep all of her appointments for Janie. If she keeps the appointments, John suffers. If she even considers some time for herself, she suffers such guilt that it is not worth it to her. Her own needs as a wife, human being, mother of a normal child, have been subjugated to what is best for Janie. Mrs. L. is a never-ending sacrifice, and John has been forced to join her. The situation is even more poignant because Janie has made progress "beyond anybody's expectations," but, of course, will always be severely handicapped. The praise Mrs. L. has received has made it even more necessary that she redouble her efforts.

What happens to the mother? Whether she prefers it or not, she has become the repository of the family's know-how about the handicapped child. She cannot refuse to take this role; her guilt would not allow it. Besides, she has no options, because there is no one to whom she can delegate it. She feels alone with her responsibility, which is essentially accurate. She really is in a "no-win" situation. Let us assume that she is sensitive to the needs of her normal children and desirous of responding to them. However, she is constantly on the run for appointments, usually made without regard for her family's schedule, as well as trying to carry out what has been suggested at home.

I constantly see mothers desperately making arrangements for baby-sitting for their normal children so that they can meet their appointment schedules for their handicapped child. I see them dubbed "overprotective" and "anxious" if they are upset when an appointment is missed, whereas they are considered "uncooperative" or "disinterested" if they cancel appointments or try to make them at times more harmonious for their family's life. They try to be home when their other children get home from school so that they do not need to try to recruit a friend or family member to greet the children. They often end up having the children come home to an empty house because they have spent hours and hours waiting for their child's appointment. Preschoolers are farmed out, or older children are pressed into service to care for younger ones so that the appointments for the handicapped child can be kept. All too often, the normal siblings are kept home from school for this purpose or brought to appointments to help the mother if the child is difficult to manage physically. She may even bring an older child with her because there is no one to care for him after school and she knows she will not be home in time, so he stays with her . . . but not for fun, or a shared experience in his interest, but because of the needs of his handicapped sibling.

With the mother-handicapped child pair split from the integral life of the family, the father and other children manage with an exhausted part-time mother whose energies are disproportionately invested in one family member. Often, the mother is unable to participate in the important "special events" in her normal child's life. She cannot go bowling with him and his group, even when all the other mothers are there, because she must be at the clinic with her handicapped child. Often, the father becomes the primary care-taker for the normal children when he is available, further isolating them from their mother, the father from the handicapped child, the siblings from each other, and the mother from the rest of her family. The normal and handicapped siblings have limited opportunity to develop a reciprocal interaction that takes into account but does not focus on the handicapped. The normal children have little chance to view their handicapped sibling as a person rather than as a continuum of appointments, therapies, and destroyers of their mother's time and energy. They end up hating and guilty.

In summary, each family member suffers not only from the handicap, but from the treatment of the handicap. Guilt is intensified and anger exacerbated. In a very real sense, the result is a handicapped family. A grim picture has been limned, one that may sound exaggerated. From my experience, it is not. Families are approached from the professional's, rather than from the family's, point of view. Let us examine what might help matters from the family's standpoint.

An important aspect of training in all disciplines might be ongoing sensitization of professionals to the effect of *treatment* on the family as a whole. Current training programs tend to emphasize the impact of the handicap on the child and family but do not study the side-effects of the treatments themselves on the life of the family. Every discipline could include, from the beginning, an orientation to the entire family and could encourage professional-family partnership in planning together, with particular emphasis on the family's feelings about treatment. We must be careful not to look solely at a spastic arm, an incontinent bowel, a shunt. Sometimes, a child is even referred to as *being* his handicap, as in "he's a spastic hemiplegic." We must move from the arm to the child to the family of which he is a part, and realize that when we treat the arm, we affect the family.

There needs to be a restructuring of service delivery patterns, from the viewpoint of family usability. Other than weekday timetables could be explored. Families could be consulted as to whether weekend services might make it possible for fathers to become involved, for their own and their handicapped child's sake, and for mothers to be freed for time to spend with their other children or for their own pleasure. Treatment should be discussed and planned together with the family and scheduled with the family's patterns in mind as well as the professional's. The practice of sending out "summons" for appointments should be abolished. Parents should be asked what times are most convenient for them and efforts should be made to accommodate them. Appointments should be kept on time. Parents and children should not be expected to wait for hours. Treatment priorities should be established and consideration given to phasing treatment so that everything is not being offered simultaneously.

Additional support personnel could be trained to relieve the parents of some of the responsibilities of therapy. Many of the daily routines could be competently handled by young people in the community with a minimum of training. Funding patterns might be altered so that such services are considered to be a family's prerogative, much as The National Foundation operated during the epidemic poliomyelitis years. Its principle was that help was offered to a family before it became bankrupt by the illness. The same should pertain to these families who are so maximally stressed.

Clinicians, among themselves, should select a coordinator of treatment for the family, preferably one who is not himself directly providing treatment, so that each clinician is not vying for control and the family is not caught in a vortex of differing opinions. Families should be honestly informed when there are differences of opinion and that rarely is there an absolutely "right" judgment in terms of medical decisions for their child.

There should be scheduled, regular reassessment of treatment goals and priorities, wherein the relative merits *and* demerits for the family are weighed. More is *not* necessarily better. We, as a society, are beginning to acknowledge the dying patient's right to refuse heroic treatment. Should we not begin to acknowledge that a family's rejection of some treatments and therapies for their child may be a healthy decision for that family? I believe that it is the responsibility of the clinician to raise the issue of the profit-loss equation to the family, to authorize and legitimatize the question as to whether a small improvement in the child is worthwhile in terms of its cost to the family in time, money, energy, and disruption.

We are all heavily invested in the value of our own treatment modality, both emotionally and economically. We must be aware of tunnel vision. It takes an insightful, honest, strong clinician to work with the family to assess the value of each treatment to the life of the child and family.

We constantly stress the importance of helping the family come to terms with the reality and significance of the child's handicap. In order that we may help them to do this, we must first come to those terms ourselves. We must be ever careful to acknowledge the limitations of our treatment and help the family to deal with the possible.

Each of us, no matter what our discipline, functions as a family counselor. Our power is profound. We are highly influential in determining the allocation of the family's resources. Perhaps we can learn to recognize that, in some cases, a better investment than physical therapy might be a family vacation. Perhaps we may come to see that, at times, a better investment than minor corrective surgery for the child might be time and money for a husband and wife to go out one evening a week. Perhaps we can begin to be more sensitive to the results of pressures that treatment imposes on the family. Perhaps we can learn to alter the kinds of treatment patterns that led Ralph to say, "I'm never going to get married. All mothers do is take children to doctors and all fathers do is pay bills." Perhaps the result might be a child, slightly more physically handicapped than he might have been, functioning more comfortably in a family much less psychologically handicapped than it might have been.

Feedback from the Family of Man: Guidance Pointers from Parents of Disabled Children

ISABEL P. ROBINAULT, Ph.D.

Summary

Letters received by social service and health agencies reveal the information gaps, alienation, and uncertainty experienced by biological and surrogate parents of children who are disabled. Responsible agencies can effectively guide parents by helping them manage their feelings and act constructively on the entire family's behalf.

Emotional and social obstacles impede parents' progress in the absence of caring and supportive professionals and organizations. Parents need partnerships with people qualified to give them the information and techniques necessary for adaptive decision-making. Guidance counselors should lead parents to appropriate resources, then stand back while parents choose their own directions.

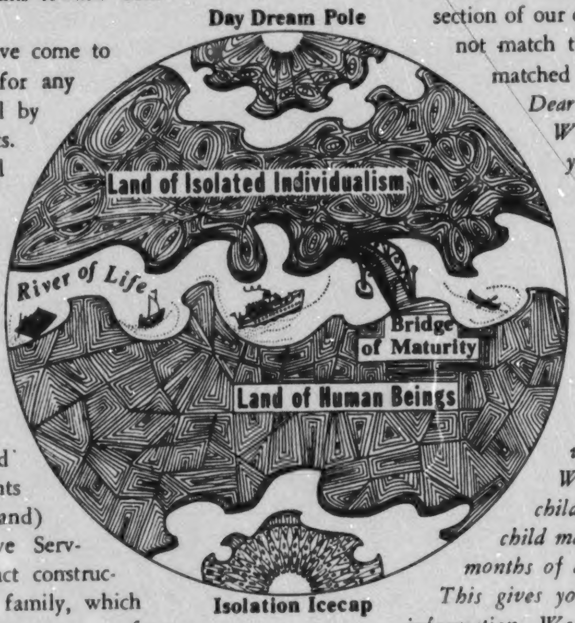
Rehabilitation Literature, August, 1968—*Isabel P. Robinault, Ph.D., was coordinator of professional activities, Medical and Scientific Department, United Cerebral Palsy Associations, New York, N.Y.*

GEOGRAPHY would have us believe that we live in a world composed of seven continents that are divided into numerous nations. But the Family of Man lives in one existential world, populated by one nation of *US FOLKS*. Here the unity stops. For *US FOLKS* is divided into the *Land of Isolated Individualism* and the *Land of Human Beings.* These are separated from one another by the *River of Life.* No one is ever born in the Land of Human Beings; one has to get to it. Therefore, it does not suffer any population explosion by automatic accumulation. No one is forced out of the Land of Isolated Individualism. Therefore, it need not fear depopulation.

However, there is much traffic across the river. In the language of the sociologists, "As babies learn to become human, they cross the gap between noncultural and cultural behavior."[1] In terms of the River of Life, many people cross passively: Some are ferried across on the rafts of their Parents. Some are steamed across in the ships of Professionals who issue health, education, and welfare passports. A few seem to float across with relative ease via the serendipitous combination of the right initiative at the right time. But the majority find it a lifetime effort of back-and-forth traffic, with the "other" side—no matter which it is at the time—always seeming better.

During World War II, soldiers in the South Pacific used to say, "The island we leave behind is always the best." And so it seems that Man's feet are still in advance of his head in the geographic world, as well as in the existential world! In spite of this trend, there are always some enterprising travelers who eventually gain two-way traffic via the *Bridge of Maturity*—and theirs are the fruits and the woes of both Lands.

As the fog of Primitive Culture lifts, or clouds of Primeval Prejudice roll back, Man develops Tools of Communication to contact both sides of the River of Life. But the number of "ships" built to date and the narrowness of early "bridges" make it a scramble. Persons who are disabled don't always come out well in this crush. However, now and then special trips are organized—or every thousandth ship is allotted to the Halt and the Meek. But it's still pretty chancy. As a result, most of the River-of-Life traffic on behalf of the handicapped is initiated via parent rafts and family floats. Lately, more of these are hitching onto Professional Ships in midstream. To encourage earlier hitch-up, Private Agencies run Life Boats and the Government recently put up HEW Lighthouses,[2] which flash family-centered beams toward Comprehensive Planning Bays.[3]



Professionals in all fields have come to realize that the earliest help for any child's development is attained by tossing a lifeline to his parents. Now *how* the lifeline is tossed is all-important.[4] Most parents never receive it prior to crisis time, and unfortunately it often is a clumsy toss that aims at an isolated problem and offers no carryover. To be effective a lifeline should be curved toward Appropriate Guidance. Appropriate Guidance has two parts: Contained Counseling, which helps parents to manage (if not fully understand) their feelings, and Supportive Services, which help parents to act constructively on behalf of the total family, which includes the child who varies in some way from normal or from average expectations.

Society uses the word *parents* collectively, and yet there is no collective approach possible. Even biological parents vary among themselves: Some of them refer to their differently developing child as "our" baby, while others speak of "my" baby or "the" baby. Those of us who are in Helping Professions are often in contact with still other parent variations—*elective* parents who assume the full care of a child with development variations, either via adoption, foster-parent plans, or grandparental ties. Some elective parents illustrate how much warmth can be offered in the Land of Human Beings by persons who may not be immediate blood relatives but who are capable of immediate relationships.

Let two letters speak directly for the writers. The first came on lined notebook paper from a rural community to the headquarters of a national private agency. The handwriting was gracious, clear, and neat. It was impartially addressed to "Dear Sir" and stated:

. . . If you have any other material that might help me I would appreciate receiving it. I have the pattern book for equipment from you.

I might be able to give you some suggestions or helpful hints if you care to have them that may help some other child with C.P.

My husband and I have cared for our little grandson since he was 14 months old and he is eight now, so we have acquired some experience and we have tried different things.

A second letter, also from another sparsely settled section of our country came on paper that did not match the envelope, but the message matched the spirit of the writer.

Dear Palsy Association,

We are foster parents of a two-year-old child handicapped with Cerebral Palsy. We have had this child since three months of age and have been seeking to learn as much as possible about C.P. This child has epilepsy also.

We do not feel she is one of the more severe cases since going to clinics we see much we have to be thankful for.

We also have in our care another child handicapped and are told this child may have C.P. also. He is eleven months of age, retarded and seizures also. This gives you a reason for our search for information. We have studied the seizures, a symptom of C.P. in this case but need to learn about the different types of C.P. in order to further our knowledge to help them.

We would appreciate (deeply) any information regarding brain damage you can send in laymen's literature to us. We will remit funds if there is a charge.

Yours truly
Mr. & Mrs. Xxx Xxxx

Through hundreds of letters pouring into a national agency, it becomes evident that whether parents are of biological or of elective origin, they have one experience in common. Parents were people before they were parents. Whatever strengths or weaknesses they had, whatever expectations or whatever environments they knew, these were carried by them into their parental experiences. So some come to parenthood prepared to leave no stones unturned, and others stumble on a pebble—either way with equal sincerity and equal integrity.

The more fragile parent has not only to cope with the maturing trend of leaving the Land of Isolated Individualism and carrying the extra burden of a disabled child into the Land of Human Beings. He also has to shed the false expectations offered by the postwar Affluent Society, which reared him to *choose* his studies, *choose* his job, *choose* his home, to expect a rational life—but never know frustration until he finds he cannot *choose* his child. In addition, he has had to buck the "no strings" freedom-from-responsibility flaunted by mass media, Hollywood, Playboy, and "Bunnies" that don't reproduce!

On top of it all, he has to bridge the present-day cultural pattern of isolated urbanity where small families see few examples of the old-fashioned, wide horizon of problems lived through, or died by. Many an urban couple have lived their work years away from residential neighborhoods, so the common sense of Dr. Spock becomes a new approach—something that is read desperately to solve an immediate baby crisis.[5] A present-day urbanization must seek new patterns and new associations to put common sense back into the living experience, since it cannot be taught in schools or bought to fit emergencies. Some of the parent-motivated organizations of this country have their roots in this search for new associations. Most of the letters coming to national service organizations are witness to emergency bridges built by those who seek written help when face-to-face contacts do not exist, have been overlooked, or have failed to establish meaningful relationships.

Nowhere is one in a better position to get feedback from the Family of Man through the letters sent by concerned parents of deviating children to some hoped-for-source of help. They speak of their immediate problems. They also speak for the condition of US FOLKS in a world society that is shifting out of its outmoded carapace but has not yet reached its new dimensions.[6] Where is the pace too slow or too fast—where, too haphazard or too erratic—where, too superficial or too tedious to interpret these parents' letters meaningfully? Clearly, they write out of present-day social patterns of *1)* Information Breakdown, *2)* Alienation, and *3)* Persistent Uncertainty.

Again, let them speak for themselves, keeping in mind that each letter is one of many similar communications, selected for its typicality. For example, this note on engraved stationery seems to refer to an Information Breakdown in strictly factual information about equipment:

. . . I would appreciate any information that is available pertaining to a wheel chair that is constructed with the chair part suspended on springs. My Pediatrician, Dr. ———, thought such a chair may be a big help in caring for my child who has cerebral palsy and has a dislocated hip. Dr. ——— was unable to find a drawing of such a chair in a book he had and so he gave me this address.

This letter can be quickly answered by sending the name and address of several wheelchair manufacturers to the parent, with carbon copy to her pediatrician and by asking manufacturers to send their catalogs to the inquirer. However, in considering problems of modern medical care, one does wonder why this inquiry had to travel interstate, via a parent. Was the doctor wisely giving an overanxious parent a reasonable task to keep her constructively employed? If not, why didn't he consult nearby rehabilitation centers for possible alternatives, since this was an unusual type of case in his practice. If overburdened specialists have no time for the functional details of care, why aren't they delegating these to qualified associated professionals? Is teamwork a school or departmental theory to be dropped in favor of Isolated Individualism? A letter cannot give an answer; it can only raise questions, which need to be followed up in the interest of the public's health and comprehensive care.[7]

Another seemingly simple equipment question came typed on neatly embossed stationery and explained:

. . . I have a son, age 4, who is crippled and mentally retarded, and we are in need of a stroller similar to a regular stroller, but it must be larger for our child.

I would appreciate any information you might be able to supply as to where we might be able to procure a stroller of this type.

Anyone with clinical experience knows that this letter *might* be satisfied on the surface by sending a list of manufacturers who have a wide size-range of strollers. There is also the possibility, however, that these parents might be evading the child's disabling condition by babying him, rather than facing reality and placing him in a junior wheelchair from which he might learn to function independently. At a distance one cannot make judgments. Therefore, a national organization with local branches would offer to put an inquirer in contact with some interested and qualified professionals near him. The final solution will be found by their thinking through the best functioning equipment for the child and the family's way of life.

Why didn't this couple approach local agency representatives in the first place? Well, our experience has been that people beset by problems often thrash far afield and don't see opportunities under their noses. People in helping professions realize this, so two-way communication is set up, between national advisory headquarters and local service units.

A last illustration of what seems to refer to simple physical needs (but may or may not) is the following neatly written note to the executive director of our agency:

. . . We are in need of a helmet for our daughter 5½

years and brain injured. We need this to protect her from further head injury. We are also in need of padding for her crib. 31 inches across the foot and 54 inches long.

Would you please send us a price list on these items as soon as possible.

Sincerely,
Mrs. Xxx Xxxx

While it is true that useful helmet information was hard to come by and our agency has only recently collected a modest number of resources, there is a curious twist to this letter. It would take half the time to buy crib padding in a local store or to order it from a catalog company than it took for this parent to look up the precise name of our national executive director. One is tempted to wonder how frequently this young parent confuses the easy with the hard problems and whether access to a parent group or a resource for Information and Referral[8] wouldn't make life less complicated and make maturing more comfortable.

Turning from inquiries about equipment to those seemingly related to information about disability, one finds a letter like this:

Dear Sirs:

I am the mother of four children, their ages are 6½, 5, 3, and 2. The last three are Cerebral Palsy children. I take them to Xxx Clinic. My oldest Thomas, 5, is Congenital Tension Athetoid Quadriplegia. The two youngest, Michael and Rose Marie, are Tension Athetoid. Michael's I.Q. is above average. Thomas is at 2½ and Rose Marie at 10 months. This year my son Thomas has started at Xxx Xxxx School. He is completely handicapped. He can't eat, dress or move himself and is still in diapers.

I would kindly appreciate any information you can send me on Cerebral Palsy. One question I have is how out of four children, I have three Cerebral Palsy?

Waiting respectfully for a reply,

Mrs. Xxx Xxxx

On looking into the origins of this letter, it soon became evident that several factors were involved: inadequate total care, ignorance, and misinterpretation of religious restrictions. An investigation revealed that the children's conditions had been correctly diagnosed and they had been given standard therapy at early ages and helped with needed appliances. Careful attention had been given their mental assessment, and the 5-year-old was started at a special school years ahead of the entrance time that many normal children in [illegible] sections of the United States start school. Each profession that these children *reached* had made a competent contribution. Each worked on a fragment of child care, but none looked at the whole family.

Inquiry revealed that it is not true that a Catholic family has to go on having deficient children in this day and age.* Family counseling combined with accepted rhythm technics (if other forms of birth control are not accepted) and careful prenatal care, as well as infant care, might have prevented or cut down on much of the tragedy that followed the first disabled child.

Fortunately, recent public health measures have set up 52 centers in the United States for maternal and infant care. These centers, in addition to private research institutes, study high-risk mothers and high-risk babies, hoping to check the past tide of uncontrolled damage.[9] But centers alone will not bring in the hard-to-reach people who need them, nor will casual medical referrals. Some parents, such as the writer of the quoted letter, will need counseling to awaken them to the need to question and the need to take action earlier. We may never know why this woman waited six years to ask, ". . . How out of four children I have three Cerebral Palsy?" Perhaps counseling resources should be taught at medical schools, so that overburdened doctors learn to use partners in the community who are willing and able to give supportive services that will work toward continuity of care. Only cooperative team work will reach those who today are unreachable by mass production methods.

In contrast, the next letter is from a person with a problem who did look ahead:

. . . Please send me some information on deformities: If a normal health girl is married to a man who was born with both his hand and foot deformed, will the children be normal like the mother or will they inherit the deformity?

If this is not the right place to receive this information please direct me to write to another Association.

The potential bridegroom is probably a spastic hemiplegia whose disability originated from stress *in utero* during the nine months before birth. His disability is congenital, rather than inherited via gene structures. However, not every case is as clearcut. Therefore, genetic clinics have been established in several major medical centers and can be located by calling social workers at local health departments.† Potential parents and also professionals must be educated to use these clinics. Sheldon Reed [10,11] lectured to parents of children with mental handicaps at Woods Schools some years ago. His words are timely today.

No counselor is clairvoyant, and none can predict the scientific discoveries of the future. The counselor cannot make decisions for the parents but he can give them facts they need in order to make decisions themselves. . . . The parents of the handicapped are helped by teaching them the biological facts and the expectations associated with the particular kind of mental retardation which has appeared in their family. [10, p. 55, 56]

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*Planned Parenthood—World Population, 515 Madison Ave., New York, N.Y. 10022

†Medical Genetics Counseling Centers. Call State Board of Health for nearest center and clinics in area, or write: American Eugenics Society, 230 Park Ave., New York, N.Y. 10017.

In addition to seeking guidance for Information Breakdowns, some parents write for relief from Alienation. For example, a recent letter states: "Some so-called friends dropped us when they discovered our child was afflicted, but some neighbors have been understanding and helpful." Not everyone is strong enough to ride over this drop from popularity. Many groups of parents who have children with disabilities have been forced together by isolation, as well as by the need to exchange information.[12] Birds will peck to death a deviant bird; primitive cultures leave deviant persons at the edge of the community where the odds against survival are greatest. However, in our Land of Isolated Individualism, we tend to look away from the disabled and their parents, easing our conscience with token donations. They are often left to seek the Land of Human Beings on their own initiative—unless, of course, compassionate neighbors or the helping professions stand by them.

An example of initiative taken on the part of a young mother who struggled against Alienation came in the following letter:

> *. . . I have a seven-year-old daughter who has Cerebral Palsy.*
>
> *She uses crutches and just recently was told she has to wear her short leg braces only at night. She is under the care of our State Health Department.*
>
> *She is the middle child of our family of nine children, the oldest 12 and the youngest 2. She has six sisters and one older brother and one baby brother.*
>
> *I love all of them dearly but somehow feel I don't always give all of them my best attention, especially Suzy. Do you have any literature or information for sagging spirits?*
>
> *Is the closest C.P. association in Monitor or Hunter? It is difficult for me to go to any meetings but would be an interested "reader" if I could find the proper literature. Thank you.*
>
> *Mrs. Xxx Xxxx*

Since it is doubtful that literature would be the solution for these very understandable "sagging spirits," it was only part of our response. By sending this letter to a competent social worker in a nearby city, several opportunities for relief were found: The disabled child was sent to a 2-week summer camp, giving the family a chance to socialize and the child a chance to learn of wider horizons; a home aide* was arranged to release the parents for monthly parent meetings, and church members responded warmly to the suggestion to drop in and to pitch in once in a while. It happened to be a social worker who pulled the strings this time. But visiting nurses, teachers of the homebound, family doctors, and church members who believe in applied religion—as well as counselors—are some of the concerned persons who are fighting alienation for the isolated all over the country. In any case, those who work together find more workable possibilities.

Life is very clearcut for a few people—the unimaginative and the lucky. Most of us struggle somewhere in the middle, trying to distinguish between mastering what can be worked out and not going down with the unsolvable. At the other end of the pendulum's swing are persons who must learn to live with Persistent Uncertainty. Parents of disabled children experience many types of Persistent Uncertainty. Among these are Differential Diagnosis, Priorities Among Disabilities, and Gaps in Services as well as in Continuity of Care. For example, compare this typewritten letter from an eastern city:

> *. . . Being the parents of a six-year-old boy, who has just recently been diagnosed as a brain injured child, we are very eager to obtain more information about the nature and needs of these children.*

with this scrawled letter from a rural western area:

> *. . . A year ago our baby was born with*
> *A—Cerebral Palsy*
> *B—Blind (Glaucoma)*
> *C—Deaf (Loud sounds in a soundproof room)*
> *D—Congenital Heart*
> *E—Some retardation (not determined)*
> *All of the above due to measles my 7th week of pregnancy. So any information you could send would be very much appreciated.*

Throughout our country there are thousands of parents who live puzzled years with children who have subtle disabilities. Too often these subtleties are not diagnosed or treated until rejection from school forces the issue. In contrast are thousands who receive specifics early because of the very gross nature of a child's multiple disabilities. Unfortunately, they find little care, since the child fits everywhere, but nowhere. In a recent article, Roger Freeman, M.D., makes an observation that is very pertinent to the uncertainty that both situations present:

> In recent years emphasis has been increasing on "early diagnosis." Unfortunately, this can be a mixed blessing or an actual disservice. Unless it results in some meaningful program, it may have only academic interest and result in

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*National Council for Homemaker Services, 1740 Broadway, New York, N.Y. 10019.

> potentially harmful distortions in parental attitudes, expectations, and child-rearing practices. This is particularly true of a wrong diagnosis; in some instances the child's needs would be better served by providing ongoing diagnosis and parental support without firm prognostication.
>
> In the event no diagnostic label is applied, a major task involves clarifying for the parents the reasons for uncertainty and an explanation of the process by which the diagnosis will be arrived at. Reassurance that lack of a "label" will not mean *lack of a program of management* [italics mine] is a basic requirement.[13]

Perhaps uncertainty is being aggravated by the social custom of relating specific services to what are still considered to be specific diagnoses. Perhaps care and services would have more meaning if professionals tried to ameliorate the lags in a child's total development.[14] Then analysis of the concurrent disabilities might prove the key to establishing priorities for help that would be consistent to a person's life, not his disease category. In either event, families need support. Useful resources for family and child care are needed from the day that some observant person notices that one child has more difficulty than another—and that could be the day of birth, if not before.

Gaps in services and lack of Continuity of Care for disabled children contribute to much of the Persistent Uncertainty that is forced upon parents. The general nature of these gaps and lags can be grasped by picking out sentences at random from a pile of letters sent by parents who still have enough bristle left to keep looking for solutions:

. . . My 7-month-old baby has been diagnosed as having a light case. He's had trouble sucking and swallowing food since birth. . . . Please send information concerning localities for treatment and how soon it should be started.

. . . We've had our 14-month-old son screened, but as you know they couldn't tell us anything. . . . Any help will be appreciated.

. . . Our 6-year-old son's last IQ was 58. The retarded school only accepts students under 50 IQ and the public school doesn't want him because he's too low for kindergarten. We're a farm family but if necessary, we will move to where he can receive some education.

. . . What provision outside of a mental institution is made for those who have to be fed and are totally dependent for physical survival—but who are more intelligent than others who can care for themselves?

. . . *William has a* mind—*he cannot speak but can type with one finger pretty fair. He is 29 and we have to find a home where he will not only get good care, but will be among friends to whom he can listen and learn and who can pay attention to him as a thinking being. . . . My health is failing. . . . We won't be here forever.*

Each of these seekers initiated a flurry of search. Some could be helped, *if* they happened to be in the right spot at the right time. Fortunately, the *practical* infant care needed by delicate disabled babies is being recorded on nursing/teaching films, while educators and therapists are assembling practical early care aids.[15]

Fortunately, life-related and family-oriented developmental evaluation centers are starting in some states, such as Missouri, under the spur of comprehensive care. Eventually the link between development and disability will be better recognized for its usefulness.[16] Then a child's fate will not hang upon one questionable test, but on a *series* of tests, repeated at *intervals*, with *learning opportunities* provided in between.[*] These will provide more reliable indices for family and community adjustment, long before school application date rolls around. Fortunately, mass state institutions are being replaced by more workable residential and day care regional units, such as those in Connecticut. These help deviant children to live in community settings, insofar as is possible, but provide inpatient service where it is the program to be preferred.

Fortunately, children are beginning to be sorted according to learning difficulties and developmental levels related to specific socializing experiences.[17] Legs, eyes, and ears will one day be adjusted or given adaptations necessary to fit into living situations and learning situations. Life will not rotate around clinics; but clinics will be set up to serve life—which is the essence of rehabilitation. Fortunately, there are brave ventures, as in foster homes, motel groupings, and work-centered residences, just getting off the ground. Watchdog committees of national agencies are working together on this aspect of Long-Term Care, since it is bigger than any one agency and is the concern of all.[†]

*Un*fortunately, this is still quite piecemeal since no one location contains a high level of such services as health, education, socialization, and vocational opportunities for any one disability—much less for persons with many disabilities. Perhaps Information and Referral services[8] that include Follow-Along Watchfulness, as set up in Detroit, Michigan, will prove useful fingers in today's service dikes. At least, they put the best heads in any locality in touch with a problem, and with one another. So while Persistent Uncertainties have no perfect solutions, the only present antidote is Persistent Search.[18]

In summary, parents need a partnership with professionals who care *and* who have technics for helping. Parents need all the facts that our present information resources can gather. They also need repeated opportunities to talk out alternatives with persons qualified to help them to make and to remake, if necessary, adaptive decisions. In case there's any question about what parents *don't* need, an excellent example of "Where Angels Fear to Tread" arrived in a recent mail:

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[*] See *Children's House* (P.O. Box 111, Caldwell, N.J. 07006), a magazine devoted to early development and education, written in lay terms, and *Today's Child* (1225 Broadway, New York, N.Y. 10001), a news bulletin presenting ideas of specialists in the child care field.

[†] See *Where the Action Is in Long-Term Care*, news bulletin of United Cerebral Palsy Associations.

I am a graduate student doing a research paper on the effects of institutionalizing a child upon the parents. For my paper I chose an actual student who is 13 and a spastic quadriplegic confined to a wheelchair. She is completely dependent upon others. Residential placement seems to be the solution. There is conflict about this within the family. I would like some information concerning placement for her, cost, etc. . . . Some basic answers to why she should be institutionalized, etc. *I need this information as soon as possible.*

Thank you
Xxx Xxxx

This, of course, is a perfect caricature of a kind of "research" attitude often popular in graduate schools—wherein the conclusion is reached and data is gathered to substantiate the shifting sands. It points out only too well why professional education has to Teach for Uncertainty, rather than promote Cookbook Clarity.[19] True, it reflects the urgency of youth to take action—any action that seems logical on the surface. Unfortunately, some of our older colleagues, in every helping profession, also belong to biased camps. The sides they take often reflect their own preferences, rather than what is needed for individuals in situations with many varying factors. Since parents must live with the decisions made, they alone have the authority to make them. Guidance is a process of contacting all resources and then standing by. Uncertain? Perhaps. But shared uncertainty responds to very human needs.[20]

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Vocational Rehabilitation Counseling and Advocacy: An Analysis of Dissonant Concepts

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Summary

The objectives of advocacy and rehabilitation are disparate despite the fact that many rehabilitation professionals have characterized them as nearly synonymous. Rehabilitation counselors are precluded from acting as consistent client advocates by the nature of rehabilitation institutions. Though professional bureaucratic organizations will not support a merger between advocacy and rehabilitation practice, practitioners working independently can be effective political advocates. This article documents the difference between advocacy and rehabilitation activities and recommends ways that rehabilitation professionals may legitimately serve as advocates for people with disabling conditions.

ADVOCACY has become an extremely popular term within the sphere of human services. Thus, it is not surprising that like other "helping" groups rehabilitation professionals have claimed a close affinity with the general notion of advocacy and have called for counselors to become more active advocates for their clients.[13,19,27,30,31,36] Apparently, the assumption is that advocacy is an implicit part of the rehabilitation practitioner's role, and that if it is not being done, it is because of counselor deficiencies of training and/or functioning.

In the following article I would like to argue that vocational rehabilitation counseling and client advocacy are inherently incongruent, and that the objectives of individual advocacy lie outside the realm of rehabilitation practice. This situation should not be attributed to counselor inadequacies but rather to societal mandates which dictate the orientation of rehabilitation practice and govern the specific parameters of the counselor's role. This is not to say that rehabilitation counselors can never serve as client advocates. It is to suggest, however, that the nature of the rehabilitation institution precludes them from consistently advocating for handicapped persons within their professional capacity.

It should be noted that I will be comparing rehabilitation practice with the stated *objectives* of individual advocacy rather than the actual practice of advocates. Unlike rehabilitation, there exists very little empirical research on the activities of advocates. After more research has been conducted on this phenomenon it may be found, as in the human services, that what advocates *say* they do and what they *actually* do are quite different. For the purpose of this analysis, however, the lack of empirical evidence is not a crucial deficiency. Rehabilitation professionals have claimed a close affinity with the objectives of advocacy and it will only be this claim that will be addressed.

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The Integration of Rehabilitation and Advocacy

Over the years there have been a number of proposals linking the activities of rehabilitation and advocacy. Wright[36] conceived of the rehabilitation advocate as one who provides the client with an ongoing relationship, or a degree of continuity, as he or she progresses through the rehabilitation system. According to that author's model, advocacy is service related, even system specific, in that the counselor is primarily concerned with client needs related to those services with which the rehabilitation counselor is most directly involved. Stone and Taylor have proposed a somewhat broader notion of advocacy. These authors have contended that counselors should advocate for their clients within any system providing services to handicapped persons. Further, the authors have called for counselors to address the environmental/social obstacles that hinder client physical and social integration. Specifically, they have suggested that efforts be directed at eliminating negative attitudes toward the handicapped, reducing architectural barriers, and eliminating unnecessarily restrictive medical, educational, and vocational requirements.[27,30]

Trela and O'Toole[31] have supported the preceding service oriented proposals. Moreover, they have suggested that reform must also occur within the existing rehabilitation and social structure if client problems are to be meaningfully addressed. The authors have argued that agency structure minimizes client participation and that counselors must help mold agency policy so that services can be provided that are most compatible with client expectations and needs. However, Trela and O'Toole have not limited their view of counselor advocacy to that which focuses only upon institutional change. The authors have proposed that reform at the agency level is actually remedial and that practitioners, to be really effective client advocates, must ultimately attend to the basic causes of injustice and poverty—namely, the larger "social, economic and political structures which breed and maintain inequality."[31, p. 246] It appears that Trela and O'Toole have gone beyond the notion of individual advocacy when they stated that rehabilitation professionals must change their person-change orientation to one of system-change. According to the authors such modifications require that "salient social statuses and seemingly immutable class-based values and political issues must be overcome."[31, p. 240]

An equally systemic view of the counselor-advocates's role has been presented by Rusalem. This author has recommended that practitioners focus upon such environmental obstacles as architectural barriers, exclusionary attitudes, family disorganization, instructional deficiencies, and ineffective services. In proposing a consumer oriented, ecological approach to rehabilitation, Rusalem has remarked that if substantial change is to occur on behalf of handicapped persons, counselors "must apply their skills to a denying society . . . through a form of counseling that has such components as confrontation, pressure, and legal action."[19, p. 184 & 188]

Within the preceding proposals to merge the concepts of rehabilitation and advocacy, there exists the implicit belief that there is a fundamental compatibility between what rehabilitation *should* be and the goals of advocacy. However, while it may be in the best interests of the rehabilitation community to claim a close affinity with the goals of advocacy, these activities are more innately incompatible than has been acknowledged in the field's literature. The major reason for this disparity is that the implicit interests underlying these activities are different, a situation which is frequently obscured within the rehabilitation field. In explaining their work, rehabilitation professionals emphasize their responsibilities to the individual and minimize their duties to the state. Thus, their responsibilities appear to be almost synonymous with those of advocates.

Another reason why the disparities between advocacy and rehabilitation have not surfaced more clearly within the literature may be due to the fact that few attempts have been made to clearly define these concepts, especially the notion of advocacy.

Client Advocacy: Definition and Emphasis

There are many different definitions of advocacy because this concept appears to mean different things to different people. As Herr has suggested this notion "abounds in conceptual and definitional confusions."[12] Blackman has observed, however, that running through all these definitions are two common themes: *1)* advocacy is an activist concept, and *2)* advocacy is an activity done on behalf of another person.[2] In sum, doing advocacy means going beyond merely calling attention to the problems encountered by another person. For if raising the issues which underlie the problems of being handicapped is all that advocacy entails, then almost every politician, public official, rehabilitation practitioner, and academician could claim to be an advocate.[32]

In order to make the concept of advocacy more explicit, Wolfensberger[35] has proposed three critical points which have clearly distinguished the advocate from other helpers. First, the advocate must possess personal fervor and strive to advance the cause of another person "as if it were one's own." Such an activity requires going beyond what would be done routinely or would be found normally acceptable. Secondly, advocacy connotes a distinct cost to the advocate, in terms of time, money, recreation, etc. Finally, advocates must be free from conflicts of interest and, therefore, must be independent of pre-existing services and service related structures.

Within the preceding discussion several important themes emerge. There is the predominant assumption that the interests of the client must be held above all other considerations. In addition, there exists the understanding that the advocate possess a sufficient degree of professional power and autonomy in order to vigorously and effectively pursue the handicapped person's best interests. Without such attributes it is doubtful that the advocate can meet his or her obligations. As Kurtz has remarked, the necessity for advocacy has arisen in response to the reality that the existing social system has *not* been evenhanded in its treatment of the disabled.[16] The important functions of the advocate, therefore, require that he or she have sufficient attributes and authority to address this imbalance.

The Nature and Emphasis of Rehabilitation Practice

The question may now be asked, "To what extent can rehabilitation counselors fulfill the requirements of the advocate position?" Before this question can be answered, however, one needs to examine the institutional pressures which are exerted upon the practitioner and govern his or her actions. Also, scrutinized should be the congruence between such pressures and the objectives of client advocacy. In addressing these and other issues I have relied primarily upon sociological inquiry into the nature and purpose of the contemporary vocational rehabilitation enterprise.

The institution of rehabilitation was designed to provide services to disabled persons in order to help equalize their chance to participate in normal societal activities. There is little doubt that this process has enabled many disabled people to make remarkable improvements in their lives through the provision of educational opportunities, medical services, crisis counseling, and vocational training. However, it should also be remembered that this institution represents the social system's formal response to its disabled members and as such it was designed to benefit society as much as handicapped people. As Safilios-Rothschild has observed:

> The societal benefit comes from the fact that rehabilitation is an institution of social control aimed at the correction of the deviance present in disabled people.[18] Their deviance is . . . potentially double. It may be only a deviation from the desirable standards of physical appearance and/or physical strength, but it may also be a potential deviation from the prescribed vocational roles and economic independence. Rehabilitation has then a basic function—the re-socialization of the disabled, that is making them able and willing to enact their "normal" social roles as effectively as possible . . . Thus it aims to minimize the degree of disruption that disability could bring about in the functioning of different social systems.[22, p. 169]

It is this societal emphasis that clearly distinguishes vocational rehabilitation from advocacy. It is this emphasis which creates pressure on the counselor to compromise the client's interests.

The rehabilitation enterprise has grown and prospered at the pleasure of society, and has done so largely because its inherent values, beliefs, and activities have remained consonant with prevailing social, political, and cultural attitudes. In order to survive, rehabilitation, like other human service activities, must remain "saleable"[22] to large numbers of people, particularly the nondisabled majority. Thus, rehabilitation agencies help people in ways that are considered most acceptable by the institution's constituents. Rehabilitation institutions, unlike advocates, have a number of different constituents—such as clients, politicians, professional groups, and the general community.

Rehabilitation Constituents

Unfortunately, the problems which disablement presents to clients and those which it presents to the institution's other constituents are often incongruent, even contradictory. As Scott has observed, the problems and needs of the handicapped involve such things as the desire to become as invisible as the nondisabled and a wish to be accepted on terms other than those based on stigma.[24] Scott argues further that for the nondisabled community the handicapped are unpleasant and often threatening. Thus, the community's dispositions toward its handicapped members are to hide them, or "at least . . . dress them up in a way that makes them more palatable . . . or less offensive."[24, p. 273]

In order to prosper, rehabilitation agencies must meet the divergent needs of their constituents. In so doing they cannot avoid favoring the interest and perspectives of the most powerful elements. Since clients are the least powerful constituents, the organization can most afford to ignore their interest. By employing such a policy they run minimal risk of seriously jeopardizing their fiscal integrity or social reputation.[24, p. 282] The degree of client involvement in the rehabilitation process is perhaps greater today because of the heightened levels of client organization and activism; however, the power of the institution's other constituents still represents a critical factor in diluting the influence of disabled persons and in determining the form, content, and emphasis of rehabilitative services.

The fact that disabled persons so frequently have no controlling interest in the development and administration of rehabilitation programs greatly influences the manner in which their problems are perceived and the way in which they are socialized to think about themselves.[6, 7, 8] In order to get services the client is expected to accept the institution's definition of his or her problem and the best solution. Thus, the handicapped individual is required to assume a status that he or she may not be used to. On the other hand, such a position may be all too familiar. Specifically, the client is accorded a status in which he or she possesses "least power, least prestige, and fewest rewards."[33]

Such circumstances are quite different in those instances where clients have become powerful, organizational constituents. In Sweden, for example, the blind have assumed control of their rehabilitation services. Within these agencies notions about psychological adjustment, total rehabilitation, accepting one's disability, and so on, have been eliminated or ignored.[24] From this example it may be seen that many taken-for-granted rehabilitation beliefs and practices are simply rejected by clients as not accurately reflecting their own reality. Such notions are only recently being seriously questioned by disabled clients who never had the inclination or power to do so within the context of rehabilitation practice.

Individualism and Social Structure

Probably the most obvious illustration of the way in which society's core values pervade and dominate the orientation or rehabilitation practice may be seen in the institution's overiding ideology—psychological individualism. The conceptions of disablement that have been constructed by American experts rely heavily upon "the ethics of individualism and personal responsibility for one's action."[24, p 286] Since the manner in which a social problem is defined and the assumptions made about its causes largely determine what is done about the problem, it is perfectly logical that the thrust of the rehabilitation enterprise in this country is directed almost exclusively at the handicapped individual rather than at the environmental conditions which are known to exacerbate the problems of disablement. As Kane has warned, "our cult of individualism" has prevented professionals from viewing the individual "as an inappropriate unit of analysis in predicting and explaining human behavior."[15]

It should not be concluded that rehabilitation professionals are not cognizant of the effect of environmental factors upon the lives and behavior of handicapped persons. Rather, it is suggested that while they have acknowledged situational factors in theory, they have done so in a way that allows them to virtually ignore these factors in practice. Ryan has articulately described such an orientation, noting that the individual's stigma is viewed as an acquired defect of social, rather than genetic, origin.[21] However, this difference, despite its historical, environmental roots, "is still located within the individual, inside his skin." As Ryan has concluded: "With such an elegant formulation the humanitarian can have it both ways. He can, at the same time, concentrate his charitable interest on the defects of the victim, condemn the vague social and environmental stresses that produced the defect . . . and ignore the continuing effect of victimizing social forces."[21] The employment of such a strategy also allows the organization to retain the enthusiastic support of its most important constituents.

The strength of the ideology of individualism represents an excellent example of the manner in which sociopolitical values may be taken for granted and accepted as universal truths even though such "facts" often vary depending upon a society's social, economic, religious, or political structure. Regarding the phenomenon of disablement, for example, Scott has observed that the "expert" conceptions of stigma in capitalistic systems tend to stress individual responsibility, while interpretations of stigma in socialistic societies seem to favor a more collective responsibility.[24]

It appears that the "facts" about disablement are not universal truths but social constructions based upon deeply entrenched, well accepted beliefs. These ideologies are based upon the system's need for coherence, conformity, stability, division of labor, and differentiated roles,[28] and are integral, unquestioned parts of the vocational rehabilitation enterprise. As I shall attempt to demonstrate in the forthcoming sections, the translation of such societal values into practice has very definite consequences for handicapped people. The exclusive pursuit of client change within a bureaucratized and professionalized context has led to stigmatization beyond that which may ordinarily be foisted upon handicapped persons. Such an outcome is antithetical to the objectives of advocacy.

Deviance Identification, Production, and Management

Like other large bureaucracies, rehabilitation organizations have become concerned primarily with prestige, success, and self-preservation.[5, 15, 22] Initially this institution was developed in response to public awareness of and concern for the most persistent problems of deviance. However, like other such bureaucratic structures, rehabilitation has become a self-perpetuating entity, has "discovered" new forms of deviance where none existed previously, and has persuaded the public of their existence and importance. In a very real sense rehabilitation agencies, in order to justify their activities, have assumed the responsibility for defining a universe of deviance. It should be noted, however, that such a universe of precise delineations is nearly impossible to determine and in fact does not exist in everyday life.[10] Friedson has articulated some of the pitfalls of such an orientation:

> In the course of defining and classifying the universe which they claim needs their services, all control agencies in effect became responsible for drawing clearer lines than in fact exist . . . and agencies may come to define people as deviant who would not ordinarily be so defined. Both professionalism and bureaucratization objectify deviance and reify diagnostic categories. In this sense while such agencies may not actually create deviant roles, they do . . . refine and clarify their boundaries and . . . add elements to the roles that may not have existed previously and so encourage pulling new people into them.[10, p 83]

It may be seen, therefore, that the agency designed to ameliorate deviance actually contributes to an exaggerated proliferation of this status upon an increasingly large number of people.

Another inherent tendency of rehabilitation systems is to impute meaning, usually debilitating in nature, to the condition of handicap. Despite the fact that not all handicapped people are called handicapped or act handicapped, the organization's pervasive labelling practices impute a specified meaning to the condition and, in effect, publicly formalize an individual's deviance and produce the assumption of a deviant role. As Friedson has noted, ". . . by labelling the individual it may organize the responses of the community toward him as a stereotyped deviant. Whereas those around him might never have attained any consensus about his behavior before, each responding to him according to his individual relationship, public labelling establishes a common focus for uniform community responses that carve out a role for him. . . . Thus, the treatment process may be said to create organizational or stereotypical behavior."[10, p 85]

The results of such labelling has been to bring together devalued people for the purposes of treatment. However, this type of intervention only serves to organize and stabilize deviant behavior rather than eradicate it. Within such situations people are brought together in order to learn from one another "the skills and attitudes of a deviant career."[9]

It may be seen that rehabilitation systems are not designed to eliminate deviance but rather restructure it to conform to prevailing societal requirements. Like other "people changing" organizations, vocational rehabilitation aims to reduce *only* the person's nonconformist patterns of conduct, disapproved values, and deviant identities that conflict with the prevailing societal values.[33]

The Counselor As Socializing Agent

Even if it is true that rehabilitation institutions are more oriented toward societal than individual needs, and even if the unintended consequences of such organizations may be to exacerbate the effects of disablement, can't committed, enlightened counselors address this imbalance, "work the system" to their client's advantage, and thereby serve as effective advocates? This seems to be the logic upon which the counselor-advocate role has been based. Thus, it is not surprising to find that client advocacy has been viewed by many rehabilitation professionals as an official part of the counselor's role.[13, p. 56]

Based on the professional ethics which guide their activities and stipulate that client interest will be held above all other considerations (including institutional interests), counselors appear to possess the prerequisite value orientations to assume the advocate's role. In fact, societal support for rehabilitation practice is based largely on the belief that *1)* their education will enable professionals to judge what the best interests of the client are, and *2)* their code of ethics will insure that they vigorously pursue the interests of their clients.[14]

Such an analysis, however, seriously underestimates the power and influence of the bureaucratic structure and grossly overestimates the autonomy of individual counselors. In conceptualizing the dynamics of the counselor's function, rehabilitation professionals have again adopted the pervasive orientation of contemporary society—psychological individualism.

Counselor-client interactions cannot be viewed exclusively as an individual enterprise and be divorced from the institutional contexts in which they occur. Within the rehabilitation dynamic, practitioners and clients are not free and equal partners participating in an open, unstructured context, and negotiating some mutually agreeable definition of rehabilitative reality. Instead, such encounters are comprised of individuals with varying degrees of power who seek to define reality for others in terms reflecting the parameters of negotiability and the conditions under which constraint will or will not be used.[25, p 34] The terms and parameters of these interactions stem from the predominant mandates that govern the bureaucratic organization and transcend the individuals within that system.[28]

Counselor-client interactions are far too important to be left to the discretions of individual participants. From the institutional perspective this encounter is viewed as the primary mechanism through which the client learns new modes of behavior. Thus, the most fundamental institutional beliefs form the basis of the client-counselor relationship[25] and the most critical task—people changing—is accomplished through human relations technologies and the deliberate structuring of counselor-client relations.[34]

That the institution is concerned with practitioner activities may be seen in the various mechanisms established to monitor counselor attributes and practices. Although such procedures have purportedly been initiated with the professional status of the practitioners firmly in mind, the primary purpose of such institutional practices seems fairly evident—staff control. These procedures include: *a)* hiring members of a particular profession known to espouse similar values, *b)* selection of individuals who appear most committed to the agency's ends, *c)* encouragement of overt manifestations of staff dedication, and *d)* maximization of personal controls through individual supervision, staff conferences, and case conferences in which guidance is provided by administrative officials who are perceived as senior colleagues rather than organizational officials.

The use of such institutional constraints upon counselor behavior is not limited exclusively to the field of rehabilitation. Such groups as teachers, social workers, and nurses are also subject to much institutional control. Hasenfeld and English have noted, however, that because of *1)* the lack of any systematic base of knowledge around their discipline, *2)* their lack of a monopoly over the field, and *3)* their lack of a strong, cohesive, and professional organization, the preceding group of "semi-professionals" are more susceptible to administrative authority than those referred to as "full fledged" professionals such as physicians, lawyers, ministers, etc. The ultimate effect of this type of professional restrictiveness is that for recipients of rehabilitation "the counterbalance provided by professional ideals and competencies to the bureaucratic omnipotence over clients may be lacking."[11]

Parsonian Framework Applied to Advocacy and Rehabilitation Practice

In summarizing the differences between advocacy and rehabilitation, I would like to employ Parson's "pattern variable" schema[17] which has been used by Kurtz to describe the orientations of advocates according to four dimensions. Kurtz has concluded that individual advocacy is an affective, diffuse, particularistic, and collectively oriented enterprise. According to the author the advocate is expected to exhibit an intense emotional commitment to furthering the interest of the disabled individual and to take action when these interests are not being met.[16] The role is clearly one of great personal investment on the part of the advocate.

A second characteristic of advocacy is the diffuse nature of its focus relative to the client's functioning. The individual right that the advocate is monitoring has been described as the most general one known to man or woman—the right to the human experience.

Advocacy has also been described by Kurtz as specific and collectively oriented. The aim of the advocate is to steadfastly pursue the client's best interest, regardless of the circumstances or obstacles. By definition then the advocate must respond to the unique needs of the individual, needs which cannot be compromised to accommodate the needs of rehabilitation programs, procedures, or personnel. Within such a framework of practice the handicapped person cannot be treated as a probability or a member of some universally defined category of people. Advocacy is not done if compromises of expediency are made which are not in the client's best interests.

The motivation for doing advocacy work is more related to the achievement of client goals than the acquisition of personal gains. Thus, according to Kurtz, the orientation of advocates is more collective than self-directed. This dimension is difficult to clearly discern in all cases, however, since for professional advocates the achievement of client interest is so intimately related to the attainment of professional gains.

Using the same schema employed by Kurtz, I would like to now describe the orientation of rehabilitation practitioners.

In the first place, rehabilitation practitioners, while trained to demonstrate concern and sensitivity toward their clients, are expected to maintain an aura of neutrality and objectivity in such relationships. Thus, the major practitioner task is not one of intense, affective, and biased involvement, as is the case with client advocates. Rather, the major objective of the counselor is to maintain warm and trustful, but impersonal relations with clients,[33] enabling professionals to respond to agency as well as individual needs.

Within rehabilitation practice the nature of the practitioner's focus is primarily upon the client's vocational life. All other client functions are secondary to his or her predicted vocational potential. In fact, it is this vocational index that dictates whether rehabilitation services will be provided at all, what type of services will be funded, and how long the services will last. Contrary to the orientation of client advocacy, which is inherently diffuse in its focus, rehabilitation programs are very specific.

Another dimension noted by Kurtz was the particularistic versus universalistic dichotomy. It is a fundamental principle of rehabilitation practice that counselors treat their clients as individuals with unique problems and needs. However, within a bureaucratic framework many disabled persons are treated more as members of some universally conceived collective than as unique individuals. Within rehabilitation organizations counselors employ orientations that Sheff has termed "diagnostic stereotypes," "normal cases," and "conceptual packages"[26] in dealing with their clients.

A person's vocational functioning is difficult to predict despite a heavy reliance upon standardized testing. Counselors often must depend upon relatively brief client contacts and professional preconceptions as the predominant hypothesis about an individual. It is this formulation upon which program decisions are made. Under such circumstances counselor perceptions are based upon what counselors think such categories of people are like; that is, what they think are the "normal cases" of such persons. Thus, the actions of counselors are legitimated on the basis of a conception of an individual as a member of a universally defined group and the probability that the individual will conform to that profile.[10, 26]

The logical extension of such an orientation is the use of conceptual packages in providing services. Within such an orientation the services that are offered to disabled people fall under rather predictable patterns and categories. In such agencies, "the conceptual units which are employed by counselors cover only a rather limited number of contingencies of disability, placement possibilities, and client attitudes."[26] This conclusion may be empirically verified by examining a sample of individualized rehabilitation plans. Such an exploration will likely reveal a consistent and predictable pattern of services that varies little from one client to another within categories of disabilities. Such practices belie any label of "individualized treatment." The realities of rehabilitation practice, including large caseloads, pressure for closures, and segregated and unimaginative vocational services have contributed to clients being treated far less individually than has been recognized or acknowledged in the field's literature.

It is likely that both professional advocates and rehabilitative practitioners participate in their activities both for the benefit of self (self orientation) and others (collective orientation). However, for advocates there appears to be less chance of conflict between functioning for others and for personal/career gains. For advocates the likelihood is great that one's pursuit of personal/career gains is very consistent with client interests. As we have seen, however, the rehabilitation counselor must frequently decide between client and organizational interest, and these are not always closely allied. For the practitioner the pursuit of personal gain in terms of career enhancement, for example, may be at the expense of the disabled individual. Further, the likelihood that the counselor will choose personal gain and organizational mandates is great since the reward systems resting within the agency are difficult to resist. For these reasons, rehabilitation professionals cannot be expected "to provide impaired persons with the loud, loyal, consistent, unwavering voice they need."[35, p. 11]

Counselor As Client Advocate

It has been concluded here that rehabilitation practice and advocacy are divergent activities and that rehabilitation counselors cannot be effective advocates in the truest sense of that concept. Does this eliminate the rehabilitation professional from serving as an advocate in any capacity? This is probably an empirical question. However, from the standpoint of most supporters of advocates the answer is likely "yes." It would be argued that professionals serving as citizen advocates outside of their practitioner roles would not be free of the conflict of interest resulting from their institutional affiliation. Further, it would likely be noted that in their capacity as advocates such individuals would be in contact with other professionals and even fellow employees who are known to them. Thus, there would be considerable pressure to "play the game." Also, there is the likelihood that a counselor's refusal to play the game combined with his or her aggressive action in behalf of a disabled person may lead to professional sanctions. Opponents of professionals serving in advocacy capacities would also argue that practitioners would bring to such a relationship the same set or assumptions about disabled people that they employed on the job. Therefore, many of the client and/or parent perspectives concerning agency procedures, practices, and decisions would be minimized or even ignored by professionals who would be used to taking such professional notions for granted.

These hypotheses regarding practitioner orientations to advocacy may be valid. However, before such a large group of potential helpers is discounted, the needs of handicapped persons must be carefully examined. I am not denying that there are likely serious difficulties and conflicts associated with practitioners serving as advocates, not the least of which may be the usurping of this activity as their own. However, I am also concerned that adherents of independent advocates may be too closed-minded about this issue, especially given the obvious needs of handicapped children and adults in the poorer and more isolated rural and urban areas of this country. Using the citizen advocate model for a moment, who is to say that professionals who are willing to serve as advocates beyond their professional duties wouldn't make the most dedicated and effective helpers? In addition to their intimate knowledge of the service delivery systems, these individuals might bring with them the strongest motivation to serve people, a need that ironically may not be being met in their professional roles.

Going beyond individual advocacy, another form of advocacy which could be conducted by rehabilitation professionals is political or system advocacy. Within the rehabilitation community political advocacy could be conducted by interested groups of practitioners acting independently or as part of the local, regional, or even national professional organizations. The emphasis of such efforts would be to provide personal links between organizations of handicapped persons, parent groups, and professional organizations. The purpose of such links would be to coordinate political lobbying efforts on behalf of disabled persons. In this way rehabilitation professionals could become more aware of the issues and activities that are of greatest concern to disabled people and provide organized support for such efforts. Ideally, such groups would operate at both local and national levels in order that regional issues facing disabled persons not be negated or minimized.

This type of organized group could have the capacity to greatly enlarge the coalition who work for social change on behalf of handicapped citizens. Politicians cannot ignore such groups. This type of coalition has advantages for both disabled persons and rehabilitation practitioners. For the disabled it increases their number of supporters and brings into their camp a politically sophisticated group with an organized structure already intact. For rehabilitation professionals such an alliance increases the number of supporters upon which they may rely for help in achieving heightened professional standing and institutional reforms. Many organizations of handicapped people are not aware of the issues confronting rehabilitation counselors. Some of these issues affect the quality and quantity of services offered to them, and which they could enthusiastically support.

Political advocacy has some advantages over citizen advocacy in that many of the actual causes of handicapism may be addressed at a policy level. In some ways citizen advocacy, because of its ameliorative nature, is like counseling in that people are so busy dealing with individual crises that they neglect the causes of such circumstances. Blatt has observed that "case by case advocacy will consume us, will play into the hands of those who want to maintain the status quo or regress further toward a segregated society." As Blatt has pointed out, it is extremely difficult on a case by case basis to address the real sources of the disabled's problems when "major policy decisions have been and continue to be anchored to institutional development and support."[3] It should not be inferred from this discussion that individual advocacy is ineffective or should be discontinued. However, the question may be asked, "Is this enough?"

Summary

I have attempted to identify the inherent differences that exist between rehabilitation practice and client advocacy. It seems important to be aware of these differences in this period of heightened client activism. Nowhere are the issues surrounding client-practitioner tensions more clearly illustrated than in an analysis of the discrepancies between rehabilitation and advocacy. Examination of this question, therefore, holds the potential for clarifying the sources of such tensions and for offering some meaningful solutions. It is also hoped that the preceding analysis will stimulate some critical thinking among rehabilitation professionals regarding the ways in which their self-interests influence their own conceptualizations and interpretations.

Finally, although a merger between advocacy and rehabilitation practice cannot be overcome within a bureaucratic and professionalized structure, practitioners working outside their professional capacities should not be summarily dismissed as ineffective individual or political advocates. Just as the professional activities of rehabilitation practitioners are governed by more than their own personal and idealistic predispositions to help people, it is probable that counselors serving as independent advocates are influenced by far more than an institutional mentality.

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Cashing in on Recovery: A Challenge for Rehabilitation

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Summary

Historically, the rehabilitation field has been nurtured by the federal government. The benefits associated with this relationship yielded a human service program that paid for itself by returning disabled citizens to productive, taxpaying jobs. The limitations of this relationship, however, have made rehabilitation services dependent on government funding for survival and have retarded professional recognition of rehabilitation counselors in the allied health community. These liabilities have been most evident during economic recession, and are characterized by lack of leadership, "crisis" management, and a reactive attitude toward issues confronting the rehabilitation field. In order for the field to survive in the emerging economic recovery, it must adopt an attitude of flexibility, efficiency, and self-sufficiency in areas of leadership, management, education, and professionalism.

Rehabilitation Literature, March-April, 1984-*Ralph E. Matkin, Rh.D., president of Vocational Management Systems, Inc. Murphysboro, Ill, was a 1983-84 Mary E. Switzer Fellow in the National Institute of Handicapped Research.*

IN THE AFFLUENCE of the 1950s and 1960s, personal income of most Americans continued to rise, lifting their standards of living. It was a period during which there was little doubt that federal and private pension programs would continue assisting individuals to maintain their acquired living standards long after they would be unable to work. It was also a time when Americans turned their attention to those less fortunate and more in need of care. Events of the mid-1970s and early 1980s, however, changed all that. Suddenly people discovered that rocketing inflation, spiralling taxation, and increased government spending were threatening their financial security. In response to these threats, calls for program accountability, fiscal austerity, and cutbacks emerged and were acted upon in both public and private business sectors.

Like many special interest groups, those in human service occupations recognized the need for federal spending deficits to be reduced, as long as proposed and actual reductions occurred in programs other than their own. For those in rehabilitation, a program created and nurtured by federal legislation designed to assist disabled citizens return to productive and independent lives, the idea of reduced government subsidy seemed unconscionable. When confronted by Executive and Congressional committee proposals that threatened to eliminate, deregulate, or relocate services for disabled persons, rehabilitation practitioners and disabled citizens alike turned to their associations and organizations for leadership, guidance, and advocacy. The purpose of this article is to discuss the impact that recent economic conditions have had on the rehabilitation field, and to propose proactive methods for amplifying the field's commitment to providing services to disabled populations.

Economics and Rehabilitation

Effects of Recession

Economic recession is defined as occurring whenever the "real gross national product (GNP) declines for two or more consecutive quarters."[22, p. 296] During the 1960s and 1970s, the American GNP rose at an annual rate of 3 percent, but in 1979 it began declining at an annual rate of 1 percent. Among the characteristics associated with such a decline are reduced consumer spending (which accounts for approximately two-thirds of the United States GNP), and increased government borrowing to continue its operations. Although the reasons for reduced consumer spending are complex and varied (e.g., cost exceeds income, supply exceeds demand), the subsequent reduction in tax revenues from sales increases federal indebtedness when spending exceeds income. Inflation and high interest rates for borrowing further aggravate this situation by keeping prices high and requiring greater spending/borrowing to maintain acquired levels of consumption. Add to this an *increased* demand for services or product consumption and indebtedness accelerates. For example, in 1979 the level of federal indebtedness was $28 billion, in 1980 it was $60 billion, in 1981 it declined to $58 billion, in 1982 it nearly doubled to $111 billion, and in 1983 it climbed to $205 billion.[10,13] Continued government borrowing at such levels is likely to keep interest rates high and force companies to delay investments in new buildings and equipment purchases—events that ultimately affect job opportunities for unemployed workers.

Perhaps the most marked effect of the recession on the American populace has been in the area of unemployment and its concomitant depletion of personal income for the unemployed. For example, when unemployment was less than 7 percent at the end of 1979, it was estimated that the rate would climb to 9.75 percent by the end of 1981.[16,17] However unthinkable the latter figure was at the time, the fact of the matter was it represented an underestimation of what occurred nationally, and even worse, what the unemployment figures were in traditionally heavy-industry centers. In the first quarter of 1981, although the national unemployment rate had risen to 7.3 percent the rates in Michigan and Detroit were 14.2 percent and 14.8 percent, respectively; by the end of that year, however, the national rate had risen to 8.8 percent while Detroit's unemployment reached 15 percent.[14] Yet, in the final quarter of 1982 the national rate of unemployment rose to 10.8 percent and dropped only slightly to 10.2 percent by April, 1983, while Michigan and Ohio continued to experience 14.9 percent and 13 percent unemployment, respectively.[2,10] Hardest hit by the recession were heavy industries such as automobile, steel, and rubber manufacturing, as well as shipbuilding. Indeed, the repercussions of high unemployment have prompted some vocational rehabilitation programs in Michigan to attempt out-of-state placement for their job-ready clients.[14]

Notwithstanding the effects of high unemployment, most economists seem to agree that industries and programs nurtured and shielded by governments become inefficient and have little incentive to hold down their costs, even when confronted by recessionary periods in the economy. According to Murray Weidenbaum, former chairman of the President's Council of Economic Advisors, government protection of such programs tends to keep prices artificially high, which acts as a hidden tax on consumers.[3] A more candid opinion by Abernathy, Clark, and Kantrow[1] insists that many of today's economic problems in public and private sectors are due to managers who perform their work using outdated assumptions and expectations. Along these lines, Rule and Wright[21] reported that rehabilitation professionals seem to be unaware of the intertwined relationship between rehabilitation and economics which, when overlooked, leads to mismanagement and misunderstanding. More important, today rehabilitation is facing a multitude of challenges that include federal budget cutbacks in all areas, manpower reductions, and plans to narrow the scope of the law that protects the civil rights of 35 million disabled citizens through the elimination or substantive revision of important enforcement provisions.[23] Confronted with such challenges, it is important to examine the efforts undertaken by the rehabilitation field to survive the recession and preserve its program integrity for persons with disabling conditions.

Rehabilitation During Recession

Since its inception in 1920, the civilian "rehabilitation program in the United States has progressed, receiving total and complete support from the federal government."[7, p. 10] A cursory examination of the political movement in this country since 1980, however, reveals that governmental intervention by its various agencies is assuming a more conservation oriented approach. According to McFarlane and Frost, proponents of this approach are characterized by governmental agency attitudes which seek program maintenance, restructuring, and retrenchment, rather than program development, expansion, and diversification. This is true especially in rehabilitation, illustrated by words such as "cost-effectiveness, impact, and accountability."[18, p. 20]

Employment Opportunities and Salaries. A report issued by the Urban Institute, forecasting the manpower needs in the rehabilitation industry, predicted that employment of rehabilitation counselors by state agencies would be limited to minimal replacement needs during the 1980s.[11] Evidence supporting a downward employment trend among rehabilitation counselor training (RCT) graduates within state-federal vocational rehabilitation agencies was noted first by Crisler and Fowler.[6] Their investigation revealed that over 80 percent of RCT graduates between 1965 and 1974 from one university were employed by state-federal vocational rehabilitation agencies. Employment in that setting among RCT graduates from the same program between 1975 and 1979, however, revealed nearly a 50 percent reduction. Employment within related agencies among 1975 to 1979 RCT graduates (34.1%) was almost double that of the 1965 to 1974 group (17.8%). On the other hand, combined employment in state-federal rehabilitation and related agencies revealed a decline from 98.2 percent (1965 to 1974 graduates) to 7[illegible] percent among the 1975 to 1979 group. Not only did these findings identify declining employment in the more traditional rehabilitation settings, but they revealed a dramatic increase in employment of RCT graduates in nonrelated work areas; from 1.8 percent among the 1965 to 1974 group to 23.2 percent among the later group.[6]

Although these findings represented employment patterns among RCT graduates from only one program, a national survey revealed a substantially less frequent tendency among 1979 and 1980 RCT graduates to work in state-federal rehabilitation agencies. In their study, Geist and McMahon[9] discovered that these more recent RCT graduates were employed in the following settings: state-federal agencies (17%); rehabilitation facilities (29%); rehabilitation-related employment (24%); private rehabilitation companies (6%); and in a variety of unrelated settings (24%). Finally, the effects of economic recession on current salaries received by RCT graduates from 1978 through 1982 were illustrated graphically in a pilot study by Riggar and Matkin.[20] Their findings revealed that, although 1979 RCT graduates currently average an annual salary of $22,000, 1980 graduates are receiving approximately $19,800 despite 1981 and 1982 graduates presently being paid $20,600 and $21,100 respectively (the latter figure being equivalent to the average annual salary paid to 1978 RCT graduates). Because these findings appeared contradictory to the notion that more work experience yielded higher salaries, the authors speculated that the recent economic recessionary period in the United States was the mitigating factor.

Rehabilitation Services Administration Activities. Following the restructuring of the Department of Health, Education, and Welfare (resulting in the formation of the Department of Health and Human Services), the Rehabilitation Services Administration (RSA) was moved to the newly created Department of Education in 1980. Early in 1981, mounting concern about the rising unemployment and increasing federal deficits contributed to Presidential proposals for disbanding the Department of Education, as well as for states assuming more of the costs for various social services subsidized largely by federal funds. Among those proposals was the Social Services Block Grant Act that initially included the state-federal rehabilitation program. If passed in its original version, individual states would have assumed a significantly greater portion of the appropriation and funding responsibilities of rehabilitation services for disabled residents in their jurisdictions. Furthermore, reduction of federal support, in lieu of increased state responsibility, threatened the availability of rehabilitation services in relation to priority within state service systems. Although concerted efforts by various independent rehabilitation organizations and advocacy associations helped to remove rehabilitation from the Social Services Block Grant Act, RSA was not among the advocates supporting exclusion of the field from the Act.[7]

In more recent years, the RSA demonstrated its lack of support to the public rehabilitation program during Congressional debate; specifically, over funding appropriations proposed in the Rehabilitation Act Extension of 1983 being considered at that time by the House Committee on Education and Labor, as well as by the Senate Subcommittee on the Handicapped. Testimony offered to both groups by RSA representatives questioned not only the effectiveness and credibility of the state rehabilitation system to provide services to handicapped clients,[8] but advised that there should be *absolutely no* federal financing of any administrative costs or salaries under the public rehabilitation system.[23] In addition to these fiscal proposals, Duncan[8] noted that RSA recommendations to eliminate the goal and all reference to age criteria for rehabilitation service eligibility prompted members of both Congressional committees to question the commitment of RSA officials to serve disabled individuals.

Finally, despite early support by RSA for the development of professional training programs for rehabilitation counselors, there are few hiring standards and regulations within the state-federal rehabilitation agency system applied to the employment of RCT graduates.[15] On the other hand, an increasing trend by RSA to dictate both the content and operation of RCT programs was noted by Daniel Sinick during an interview with the immediate past executive director of the National Rehabilitation Counseling Association.[5] Needless to say, when the funding sponsor of RCT programs does not encourage or require state agencies under its jurisdiction to hire only those persons trained in rehabilitation fields, especially during a recessionary period, it is not surprising to observe fewer RCT graduates working in those agencies.

Rehabilitation and the New Economy

Evidence of Economic Recovery

In May, 1983, the estimated GNP for the first quarter was revised from a 3.1 percent increase to 2.5 percent; yet, the more conservative prediction included an $8 billion decline in manufacturing inventories.[10] What this suggests for the national economy is that without a backlog of unsold goods, firms will have to hire more workers in order to increase production to meet a slow but steady rise in consumer spending. More importantly, the predicted growth of the GNP for the second quarter is estimated to approach 6 to 7 percent, which approximates what postwar recoveries have averaged during the first year following a recession.[10] Other indicators of an emerging economic recovery are the fact that manufacturers used 71.1 percent of their productive capacity in April, 1983, which is the highest level attained in the previous 13 months; the average number of working hours per week spent in manufacturing jobs rose from 39.6 in March to 40.1 in April; and current mortgage rates average 13 percent annually compared to 18 percent in October of 1981.[10]

More production activity also will help unemployment rates decline from their present level of 10.2 percent to approximately 8.5 percent by the end of 1985, according to Data Resources, an economic forecasting firm.[2] With the advent of new technologies and an apparent irreversibly reduced heavy industry labor market, the largest proportion of new and expanding job markets are being created in service industries such as health care and data processing. In fact, a preliminary report developed by the Department of Labor predicted that in 1995 there will be nearly 28.5 million people employed in service jobs (compared to 19.5 million in 1983) versus 22 million people working in manufacturing trades.[2] In order to survive in the new economy that will emerge with recovery, individuals and programs will have to be flexible and efficient, ready to take advantage of new technologies and consumer demands. These requirements are applicable to the rehabilitation field as well.

Challenges for Rehabilitation

In spite of a predicted increase in available service-type jobs, most are expected to be relatively low paying occupations, without necessity for a college education, such as nurses' aides, janitors, sales clerks, cashiers, fast-food workers, and waiters.[2] In fact, the federal government's Scientific Manpower Commission predicted that in 1992 there will be approximately 3.3 million more graduates than jobs requiring a college education.[19] Thus, competition for jobs may require many to accept low-paying, low-prestige employment initially, especially among those college graduates without specific skills, experience, or marketable talents. For persons entering into or currently employed within the rehabilitation field, the challenges confronting professional survivability in a more flexible and efficiency-oriented economy are in the areas of leadership, management, education, and professionalism.

Leadership. The effects of the recent recession have reinforced allegations that the rehabilitation field presently lacks a single, unified voice to communicate its needs effectively to the public. Much of the problem seems to focus on the proliferation of organizations and associations purportedly representing a limited number of special interest groups, groups which appear to coalesce only in times of crisis. Emerging from the large number of independent rehabilitation and rehabilitation-related groups are an array of goals and objectives, many of which are redundant, and some of which are inconsistent between seemingly related organizations. Until such time that the rehabilitation field resolves its internal differences by identifying and working toward a common goal, the future of rehabilitation appears uncertain in terms of acquiring broad-based political support and public recognition.

A proposed method by which the rehabilitation field can move toward attaining a single unified voice and more effective and efficient leadership potential is through consolidation efforts among the many independent professional rehabilitation associations. Two levels of consolidation are recommended: *1)* a single organization restricted to direct and indirect rehabilitation service providers, such as administrators, counselors, placement specialists, nurses, and vocational evaluators; and *2)* a consumer/paraprofessional advocacy group consisting of persons interested in the rehabilitation of disabled persons. The former organization conceivably could be called the "American Rehabilitation Association," and the latter association titled the "American Federation for Citizens with Disabilities." Formation of these two organizations could facilitate achievement of recommendations made by McFarlane and Frost[18] that include consolidation of multiple funding sources, clarification of all rehabilitation goals and expectations in service delivery, and generation of greater impact on legislative bodies responsible for rehabilitation funding allocations.

Management. Despite the fact that federal funding authorizations and recommended appropriation levels for public-sponsored rehabilitation programs continue to increase from one year to the next, they also continue to be insufficient to carry out program objectives designed to benefit increasing numbers of eligible clients. In order for the rehabilitation field to survive in the years ahead, effective leadership must include efficient management of resources and personnel. Attention to cost containment of rehabilitation services and programs must be present at all levels of practice (i.e., among administrators, educators, practitioners, and supervisors) regardless of employment setting. In order to achieve management efficiency, rehabilitation personnel must be prepared to scrutinize their manpower needs at all levels of operation, to identify training needs for staff and clients alike, and to justify expenditures of funds for all in terms of identifiable rehabilitation goals.

Education. Recently, the Department of Labor reported that people today are changing jobs four times during their work careers.[2] For those so affected in the rehabilitation field, the transition may be made less threatening by training programs which provide greater coordination between course work and rehabilitation services applicable to diverse settings and in a variety of delivery systems (e.g., disability compensation and state-federal rehabilitation systems). On the other hand, the Department of Labor findings suggest that retraining will become a permanent part of American business and society—a situation that can be advantageous for persons educated in vocational guidance and placement services. Moreover, under the Jobs Training Partnership Act of 1982, new programs will strive to prepare people for jobs in private companies, with business executives performing a major role in shaping the training.[2] Working with employers in a training capacity, rehabilitation professionals have an opportunity to demonstrate the cost-saving benefits of rehabilitation principles and techniques applied to industry; services that could be paid for from the $3.5 billion budget proposed for the first year of the Act.

Educational issues also must include an assessment of the future directions of disciplines within the rehabilitation field. When rehabilitation counselors, for example, have had the opportunity to forecast the future of their discipline, their concerns focus on appropriate practitioner training and RCT curriculum content. In a study conducted by Anderson and Parente,[4] rehabilitation counselors indicated a belief that RCT programs would become highly specialized with counselors being trained in one disability area, and a greater number of nontraditional employment settings employing rehabilitation counselors as part of their staffs between 1985 and 1989. Currently, evidence already exists suggesting that rehabilitation counselors are seeking and finding employment in such diverse settings as insurance companies, railroads, industrial firms, and private practice, to mention a few. Skills being required by employers of rehabilitation counselors include job analysis, job modification, job restructuring, vocational counseling, job placement, interpretation and application of medical information, employee assistance programming, evaluation of employees' and/or applicants' work potential, and an understanding of personnel selection rules and regulations.[12] More importantly, RCT and related rehabilitation educational programs must be prepared to adapt their curricular content to adequately prepare graduates for employment in a rapidly changing technical job market.

Professionalism. Confronted with increasing demands for specialized knowledge and skills to adequately serve the unique needs of employers and client disability groups, especially in a marketplace that is saturated with college graduates, rehabilitation practitioners can enhance their employability by possessing recognized post-graduate credentials. The Anderson and Parent study[4] predicted that between 1985 and 1989, employment opportunities for rehabilitation counselors who are not certified will be minimal. Additionally, one of the proposed amendments of the Rehabilitation Act Extension of 1983 recommends the insertion of the word "qualified" before the word "personnel"; a revision intended to encourage educational and/or experiential upgrading of rehabilitation professionals providing services to disabled clients.[8] Accreditation of rehabilitation educational and service programs is another method by which consumers potentially will assess the professionalism of the field. Along those lines, rehabilitation counselors predict that between 1985 and 1989, accreditation by the Council on Rehabilitation Education will be a major determinant in student enrollment in RCT programs.[4] Similarly, client referrals by many state agencies to rehabilitation facilities frequently are determined on the basis of facility program accreditation by the Commission on Accreditation of Rehabilitation Facilities. The rehabilitation field as a whole, however unfortunately, is far from acquiring professional status—a problem that incorporates its reactive approach to issues confronting the field.

In order for the rehabilitation field to begin moving toward professional recognition, and in so doing begin to initiate control over its destiny, steps must be taken to unify the many independent rehabilitation groups. One potential method is through the consolidation of the major rehabilitation associations under an umbrella organization, possibly titled the American

Rehabilitation Association, composed of divisions representing rehabilitation administration, counseling, job placement, nursing, occupational therapy, physical therapy, vocational evaluation, work adjustment, and the like. Another closely related potential consolidation effort could be the merger of rehabilitation credentialing agencies under an umbrella agency, possibly titled the Rehabilitation Credentialing Board. This Board could be composed of three related commissions variously titled the Rehabilitation Certification Commission (granting specialty certifications to practitioners), the Commission on Accreditation of Rehabilitation Services (granting accreditation to service programs), and the Commission on Rehabilitation Education (granting accreditation to rehabilitation educational programs in various disciplines). Most importantly, the consolidation of rehabilitation associations and rehabilitation credentialing agencies into two related groups could strengthen the relationship between educational training and service delivery, as advocated by McFarlane and Frost.[18]

Conclusions

The creation, development, and growth of the rehabilitation field are the results of federal sponsorship and concern for improving quality of life for disabled citizens. Moreover, governmental support has allowed the rehabilitation field and occupational groups within it to begin moving toward attainment of professional recognition by the health care community. Despite this necessary and early nurturing, the rehabilitation field has been remiss in developing self-sufficiency, choosing instead to continue its dependency for survival on federal funding that fluctuates from year to year and from one administration to another. Furthermore, by failing to take charge of its own professional destiny, the rehabilitation field has become susceptible to efforts by political lobbyists and others to restructure, reduce, or eliminate its service programs and eligible client populations, as well as the training programs and qualifications required to practice as rehabilitation professionals.

These problems have been especially evident during the recent economic recession, and have prompted many to question the effectiveness of the field's leadership and management capabilities. These criticisms, indeed, have contributed to fragmenting the field through the proliferation of independent and frequently redundant rehabilitation groups and associations. In order for the rehabilitation field to survive as a viable service program in an economy that will emphasize flexibility and efficiency, it needs to develop its own Individualized Written Rehabilitation Program (IWRP), as recommended by Wright and Rule.[23]

The goal advocated for rehabilitation's IWRP is *PROACTION*. The objectives identified to achieve the goal include: *a)* consolidation of organizations comprised of direct and indirect professional rehabilitation service providers; *b)* consolidation of rehabilitation credentialing agencies into a single body; and *c)* merging rehabilitation consumer and paraprofessional groups. The unification of the rehabilitation field, under these three objectives, will establish a rallying point for over 35 million disabled Americans, result in a single voice for rehabilitation issues, and create a lobbying force designed to lead, rather than react to, governmental issues affecting services for disabled populations.

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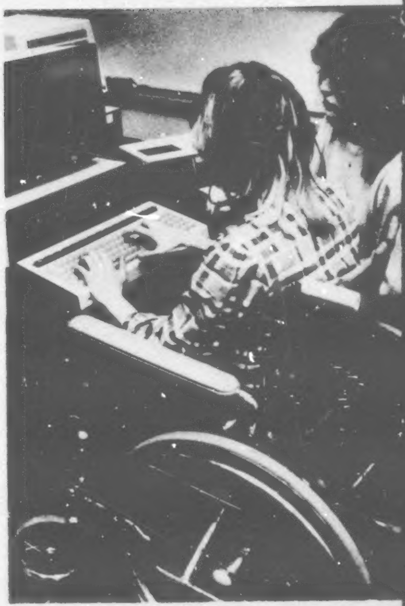

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